

CHILDREN WITH MOTOR HANDICAPS

Epidemiological, medical and socio-pædiatric
aspects of motor handicapped children in a
Swedish county

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PART ONE

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INTRODUCTION

Parallel with improved socio-economic conditions, better nutrition, housing and care, infant morbidity and mortality have dramatically diminished during the last 100 years in industrialized countries.

In the changed panorama of childhood disease the chronic disorders and handicaps have become more important due to the relative increase, to their impact on the family welfare and on the health care system. Thus, children with chronic illness or disabilities comprise at least 5-10% of the population under the age of 16 (1, 2). Motor disorders account for a major part of chronic disorders in childhood (1).

In the 1950s and 1960s similar frequencies of cerebral palsy (CP) have been reported (3, 4, 5, 6, 7, 8, 9, 10, 11). It has been feared that intensive neonatal care - resulting in lower infant mortality - could lead to higher frequency of handicaps in the surviving children, e.g. by brain damages (12, 13, 14). Recent reports by Hagberg et al. (15, 16, 17, 18) argue against this contention.

The incidence of spina bifida cystica (SBC) varies geographically (19, 20). There is also a great variation of infant mortality in this group, due to medical progress but also to selection for treatment in e.g. the U.K. (19, 21, 22, 23, 24).

In 1966 I made a survey of motor handicapped children in the Malmöhus county council area (MLL) (10, 25).

The purpose of the present investigation was to make a comparable but also socio-pediatrically extended study - 10 years after the first one - of children with motor handicaps, of the same age groups, in the same area.

HISTORICAL REVIEW

Cerebral palsy (CP) seems to have existed throughout all history. In ancient Egyptian reliefs there are pictures of persons with signs of CP (26).

The masterpiece painting by Ribera (1588-1656) in the Louvre "Le pied-bot" ("The club foot") magnificently shows a spastic hemiplegic boy. This was pointed out already by Sigmund Freud (27).

William John Little published ingenious observations and thoughts about CP and its cause in his classical: "On the influence of abnormal parturition, difficult labours, premature birth, and asphyxia neonatorum, on the mental and physical condition of the child, especially in relation to deformities" (28). At that time he had a long practical experience of - and had given famous lectures about - children with CP.

Little (28) drew attention to Shakespeare who in his play "King Richard III" describes the king as a spastic hemiplegic person. He also ascribes the troubles to pre-

mature birth, feet first and the fact that life was elicited only with great difficulty. Thus, perinatal brain damage seems to have been a known cause of motor handicap already at that time - at least to a genius like Shakespeare.

Cazauvielh's description of hemiplegic CP in "*Recherches l'agénésie cérébrale et la paralysie congéniale*" (1827) is judged by Freud (27) to be the first important medical paper about CP.

Sigmund Freud gave us an epoch-making and astonishingly modern "historical" paper in his: "*Die infantile Cerebrallähmung*" (27). There he proposes a classification system of CP that is essentially still accepted today; developed further and adopted to modern knowledge in significant papers (16, 29, 30).

In Scandinavian literature a comprehensive historical review about CP has been given by Erik Hansen (7).

In "*Spina Bifida for the Clinician*" Brocklehurst (19) has written an extensive historical review. He thinks that Nicholas Tulp was the first to give a concise description of spina bifida in his "*Observationes Medicae*" from the middle of the 17th century.

DEFINITIONS, CRITERIA AND CLASSIFICATIONS

DEFECT, DISABILITY AND HANDICAP

Younghusband et al. (31) has given the following definitions that are accepted also for this study:

"A defect is some imperfection, impairment or disorder of the body, intellect or personality;

A disability is a defect which does result in some malfunctioning but which does not necessarily affect the individual's normal life;

A handicap is a disability which for a substantial period, or permanently, retards, distorts or otherwise adversely affects normal growth, development or adjustment to life" (31).

DIAGNOSTIC GROUPS

Cerebral palsy (CP)

In this investigation cerebral palsy (CP) is defined as permanent impairment of movement and posture resulting from a non-progressive brain disorder - due to hereditary factors or events during pregnancy, delivery, neonatal period and the first two years of life. Identical or similar definitions are used by several investigators (7, 9, 10, 15, 17, 25, 30, 32, 33).

The classification of the CP syndromes is based on clinical signs in accordance with a system generally

accepted in Sweden (29) - based on that of Freud (27) - and newly reviewed and used in significant papers (15, 17, 32, 34).

Spastic (hypertonic) syndromes

In this group spasticity is the dominating feature. In the hemiplegic group the symptoms are onesided while in the tetraplegics all four limbs are involved, the upper limbs showing the same or more severe symptoms than the lower ones. This group has been designated bilateral hemiplegia by Ingram (9). All cases where the lower limbs are more affected than the upper ones are assigned to the group diplegic spastic CP.

Ataxic syndromes

Ataxic CP: A syndrome dominated by inco-ordination of voluntary movements, i.e. signs of dyssynergy such as dysmetria, unsteady gait and marked intention tremor of the upper extremities. Ataxic CP is subdivided into congenital (simple) ataxia, ataxic diplegia and the dys-equilibrium syndrome (9, 34).

When ataxic symptoms dominate but also spasticity of diplegic distribution is found the diagnosis is said to be ataxic diplegia.

In the dysequilibrium syndrome incapability of or pronounced difficulty in maintaining an upright body position and in experiencing the position of the body in

space dominates the condition. Full length falling occurs for many years without any tendency towards compensatory movements of protection (35, 36).

Dyskinetic syndromes

Athetosis is defined as a syndrome with inco-ordinated generalized hyperkinetic movements of choreatic and/or athetoid kind. The muscular tone is normal or hypotonic. Thus, the term athetosis is used in the same way as by Hagberg et al. (15).

More severely affected dyskinetic CP children are referred to the dystonic ("tonus changing") syndrome. Dystonic traits, tension shifts and persistent neonatal reflex patterns dominate the clinical picture. Dystonic children also with pronounced athetoid hyperkinesias are in this investigation said to have dystonic + athetotic syndrome. The dystonic ("tonus changing") and dystonic + athetotic children have often been reported under a common heading (10, 15, 17).

Mixed forms of CP

Included under this heading are those children with CP who are severely motor handicapped with mixtures of spastic and/or ataxic and/or dyskinetic symptoms.

Spina bifida cystica (SBC)

Spina bifida cystica (SBC) includes children who are born with a myelomeningocele and who have a remaining motor handicap. (However, for the incidence and prevalence calculations all children with SBC - also with meningocele - were taken into account).

Other motor handicaps (OMH)

Under the heading of other motor handicaps (OMH) are reported permanently motor disabled children neither having CP nor SBC.

Not included in the survey are children with only minimal brain dysfunction (MBD). Children with luxation of the hips, flat feet, fractures and similar disabilities are also excluded, as well as children whose locomotion abilities are reduced by e.g. heart failure, cystic fibrosis or asthma.

SEVERITY OF HANDICAPS

Severity of motor handicaps

Children who cannot walk at all or only with maximum support or whose best hand has no purposeful function are said to have a severe motor handicap.

Moderate motor handicap have those who can walk with some support (crutches or sticks) or who have a bad function (a very clumsy grip) in the best hand.

All the rest of the motor handicapped children are said to have a slight motor handicap.

Intellectual capacity; mental retardation

Children who are not mentally retarded are divided into two groups, normal (IQ roughly exceeding 90) and dull (IQ roughly 70-90).

In accordance with often used criteria children are said to be mentally retarded when their IQ is roughly below 70. A mild mental retardation is assigned to children with an IQ of roughly 50-69; while children with IQ roughly below 50 are said to have a severe mental retardation (37, 38).

Associated handicaps

Handicaps other than motor ones are recorded as associated handicaps. They are grouped in neurological (mental retardation, epilepsy, visual, hearing and speech disturbances), psychological (extreme slowness, concentration, perception and behavioural problems) and other problems (e.g. extremely bad memory, intense anxiety and uncertainty, severe dribbling, high degree of obesity, severe VOC, severe pressure ulcers and incontinence problems).

Not listed among associated handicaps are early operated hydrocephalus among children with SBC (83%) nor are squint (per se) or slight refraction and sight disturbances recorded.

The associated handicaps are graded as slight, moderate or severe.

When severe the associated handicap demands special care and treatment and leads to a severe total handicap even in a slightly motor handicapped child. Thus, severe associated handicaps consist in children with e.g. severe mental retardation, epileptic convulsions weekly or more often, very severe sight disturbances or blindness, severe hearing impairment (with need of hearing aids) or deafness, children without useful talk etc. Slight associated handicap implies some impairment - without apparent impact on the handicap situation nor need of special training, treatment or aids. For the rest of the motor handicapped children (with recorded associated handicaps) the associated handicaps are said to be moderate.

Epilepsy

All children who had had repeated seizures are said to have epilepsy except those who - without use of anti-epileptic drugs - had not experienced any seizures during the last two years (preceeding the investigation).

Activities in Daily Living (ADL)

Some motor handicapped children are independent of assistance with regard to all ADL-activities. Others have a slight dependency (e.g. can eat by themselves, manage their undressing, washing and going to the lava-

tory) but are at least in one ADL respect depending on some help from another person. Those children needing full assistance in one or two ADL respects are said to have a moderate ADL-dependency. Totally ADL-dependent are those children needing help from another individual in all ADL respects.

Total handicap

A slight total handicap is recorded only in the children with a slight motor disability, normal mental capacity (dull included, IQ roughly 70 or more), no more than a slight other associated handicap and independency concerning ADL-activities. A severe total handicap is designated to all children with a severe motor handicap and/or a severe mental retardation (IQ roughly below 50) and/or one or more severe other associated handicaps and/or total ADL-dependency. All the rest are said to have a moderate total handicap.

Social classes

For socio-economic classification the 3-graded system (39) which is commonly used in Sweden has been employed here. This system considers the occupation and indirectly the education and economy of the father in the family. When the mother is single, the socio-economic classification is based on her circumstances. The socio-economic difference between the three groups in Sweden is not pronounced. The applied socio-economic grouping system

has been used in an extensive epidemiological study of child health in the same (MLL) area (40).

Weight related to gestational age

The classification of the child as appropriate (AGA), light or heavy for gestational age was done according to the Swedish standard curves (41), illustrated in Fig. 8.

Pathogenetic classification of CP

The pathogenetic classification of CP was done close to that of Hagberg et al. (15, 17), and the one used by Cussen et al. (32). Prenatal factors were considered to be the cause when clear prenatal CNS malformations were found; when the child was born light for gestational age (<-2 SD) and no obvious peri- or postnatal cause was found; when there was an uneventful history and an identical CP syndrome in siblings; when obvious abnormalities were noted during pregnancy and the peri- and postnatal history was normal.

Perinatal factors were considered to be the cause when obvious abnormalities during delivery and/or the first week of life were noted; when children of very low birth-weight (VLBW = 1 500 g or less) were appropriate for gestational age (AGA) and had a normal pre- and postnatal history.

Postnatal factors were considered to be the cause of CP when clear brain damaging events had occurred when the

child was 8 days - 2 years of age. Factors causing the CP was said to be untraceable in children with birth weight 1 500 g or more, appropriate for gestational age (AGA) with normal pre-, peri- and postnatal history.

Age groups

In this study children of preschool age (preschoolers) are children born 1969-72 (~4-6 years of age).

Children of school age (schoolchildren) are those children born 1960-68 (~7-16 years of age).

Area studied

The southernmost county council area of Sweden is that of Malmöhus (MLL; Fig. 1; the city of Malmö does not belong to the area).

Of Sweden's 8.2 million inhabitants, 0.5 million (1976) live in MLL - making it one of the most densely populated areas of the country. There are 104 inhabitants per square km; 20 per square km being average for the whole country. Relatively more people are working in agriculture in MLL than in the rest of Sweden (8.6% vs. 6.4% agriculture, forestry, etc.). There are two large cities (>75 000 <100 000 inhabitants), one (Lund) with a university hospital and a paediatric department having an intensive care unit and a section for habilitation and child neurology. In 1976, 77.5% of the county tax

revenue was used in the health and medical care sector, compared to an average of 75% for the whole of Sweden (42).



Fig. 1. Investigated area of Sweden (MLL; population 0.5 million)

Date of study

The investigation reflects the circumstances for the motor handicapped children in MLL on April 1, 1976.

METHODS AND CLINICAL MATERIAL

In 1964-65 a special committee compiled an inventory of handicapped people in MLL (43). Handicapped persons were located through their special organizations, schools, the regional social insurance office, doctors and nurses in the district health service, child welfare centres, social and child welfare boards, the County Council Board for Provisions and Services to the Mentally Retarded, paediatric, orthopedic and other departments dealing with handicapped people. From data collected I drew up a county register of motor handicapped children. In 1966, I performed a comprehensive survey of motor handicapped children in the MLL area (10, 25). Working on with these children (as a neuropaediatrician at the assessment centre for motor handicapped children; as consultant at the neurosurgical department and at the county council's home for mentally retarded) has enabled me to follow their progress closely. A check-up was done with physiotherapists, social workers, doctors and psychologists dealing with problems of motor handicapped children before the present investigation was performed in 1976, 10 years after the first one. All motor handicapped children, having CP, SBC or other motor handicaps (OMH), being 4-16 years of age (born 1960-72) and living in the MLL area, were investigated and assessed by me. The series is unselected and complete - including also all severely mentally retarded motor handicapped children (also those at

For incidence and prevalence calculations for CP, the last 10-year period of the study was used, for the SBC children the last 5-year period (when all were registered for certain).

Children with suspected mental retardation and more than one third of the others - 146 in all - were examined by experienced psychologists, often using one or more of the following tests: Terman-Merrill, WISC, Leiter, Raven or Griffith (44). Half of the untested were slightly totally handicapped children with CP. The children with OMH had the lowest test frequency (30%). The majority (70%) of all the untested - judged to have normal mental capacity - were schoolchildren with obviously normal intellectual function in school. Almost all (94%) of the children with CP of this group had a slight motor handicap.

Questions were asked for extreme slowness, concentration, perception and behavioural problems. Though no systematic psychological assessment was made, obvious problems in these respects are likely to have been reported by teachers, preschool teachers, psychologists, social workers and others.

Of the 207 children in the area with CP or SBC 197 (CP 174; SBC 23) were investigated with special reference to socio-pediatric circumstances. Semistructured interviews were made with care-giving parents, i.e. biological, adoptive or foster parents of these children.

The interviews were performed at home visits by a habilitation social worker. The findings are reported in Part Two.

All data were gathered in special forms, punched on tape and tabulated on a Univac 1100 computer.

In the statistical treatment Chi-square analyses, with Yate's correction where applicable, were used.

PART ONE

EPIDEMIOLOGICAL AND MEDICAL ASPECTS

ON CHILDREN WITH MOTOR HANDICAPS

CHAPTER I

MOTOR HANDICAPPED CHILDREN:

NUMBER, FREQUENCIES, SEX, SEVERITY OF MOTOR
AND MENTAL HANDICAPS

The southernmost county council area of Sweden (MLL; Fig. 1) in 1976 had 0.5 million inhabitants; 89 500 were children born 1960-72 (4-16 years of age). Of them 266 (0.3%) had a motor handicap, most often due to CP (68.8%); 9% had SBC and 22.2% OMH (Table 1).

Table 1. Motor handicapped children in MLL. Number and percentage

Diagnosis	n	%
CP	183	68.8
SBC	24	9.0
OMH	59	22.2
Total	266	100

The number of CP, SBC and OMH per birth year is shown in Fig. 2.

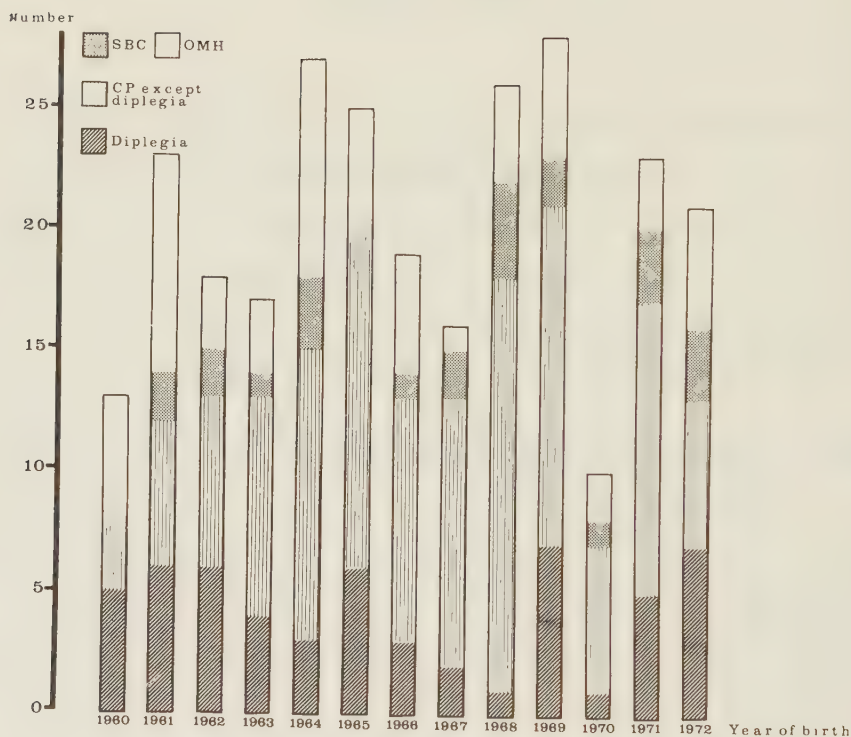


Fig. 2. Number of motor handicapped children per year of birth

Table 2 shows the number and percentage of the various types of CP. The majority of children with CP had spastic symptoms.

Table 2. Diagnosis of children with CP in MLL. Number and percentage

CP, type	n	%
<u>Spastic</u>	<u>119</u>	<u>65.0</u>
Hemiplegic	55	30.0
Tetraplegic	8	4.4
Diplegic	56	30.6
<u>Ataxic</u>	<u>19</u>	<u>10.4</u>
Diplegic	9	4.9
Congenital (simple)	6	3.3
Dysequilibrium	4	2.2
<u>Dyskinetic</u>	<u>34</u>	<u>18.6</u>
Athetotic	17	9.3
Dystonic (tonuschanging)	7	3.8
Dystonic + athetotic	10	5.5
<u>Mixed forms</u>	<u>11</u>	<u>6.0</u>
Total	183	100

A disease in or damage to the nervous system was the most common cause of OMH (Table 3). About one third had a muscular disease (muscular dystrophy, atrophy or myositis). Hereditary factors caused the motor handicap in over half of the children with OMH.

Table 3. Diagnosis of children with OMH (other motor handicap than CP or SBC) in MLL. Number

Diagnosis of OMH	n
Progressive muscular dystrophy	9
Dermatomyositis	1
Spinal muscular atrophy	8
Ataxia (VOC; teleangiectasia; Friedreich's)	3
Sequel to brain tumor	5
" " cerebral aneurysm	1
" " syndrome of the anterior spinal artery	2
" " nerve trauma	4
" " accidents (traffic)	5 (3)
" " poliomyelitis	2
" " juvenile rheumatoid arthritis	3
Phocomelia (thalidomide)	5 (4)
Other malformations (sacral agenesis)	5 (3)
Arthrogryposis	1
Osteogenesis imperfecta	1
Achondroplasia (Mb Ollier)	1
Gargoylism	2
Amputation of one leg (sarcoma)	1
Total	59

Frequency of occurrence of motor handicaps

The frequency of motor handicapped children per year and 100 000 inhabitants was 4.1 (Table 4).

Table 4. Number of motor handicapped children and frequency per year and 100 000 inhabitants in MLL

Diagnosis	n	Frequency per year and 100 000 inhabitants
CP	183	2.8
SBC	24	0.4
OMH	59	0.9
Total	266	4.1

Incidence (related to the population born in MLL) and prevalence of the motor handicapped children with CP or SBC are shown in Table 5.

Table 5. Number and frequency of CP and SBC related to the population born in MLL (1963-72: n=64 906; 1968-72: n=32 668)

Diagnosis and year of birth	n	Incidence /1 000	(dead before 1/4-76) n	n	Prevalence /1 000
CP 1963-72	123	1.9	(6)	117	1.8
SBC 1968-72	18	0.6	(4)	14	0.4

The incidence of CP, 1.9 per 1 000, is the same for the five-year-period of 1963-67 compared to the period 1968-72. That, and the incidence of the different types of CP is shown in Table 6.

The incidence of live born children with SBC (myelomeningo- and meningocele) was 0.6 per 1 000.

More children with spinal muscular atrophy than muscular dystrophy were born. Since the first group had a higher early mortality, the prevalence was the same (0.13 vs. 0.14 per year and 100 000 inhabitants).

Sex

There were more boys than girls among the motor handicapped children (Table 7). This was true regardless

Table 7. Boy/girl ratio among motor handicapped and all children (4-16 years) in MLL

Diagnosis		Boys %	Ratio boys /100 girls
CP	n=183	54	118
SBC	n= 24	58	140
OMH	n= 59	64	181
Total n=266		57	131
All children in MLL n=89 500		51	105

Table 6. Incidence of CP in MLL. Number and per thousand

CP, type	1963 - 67		1968 - 72		1963 - 72	
	n	Total live born: 32 238 per 1 000	n	Total live born: 32 668 per 1 000	Total per 1 000	
<u>Spastic</u>					<u>1.22</u>	
Hemiplegic	18	0.56	18	0.55		0.55
Tetraplegic	7	0.22	5	0.15		0.18
Diplegic	13	0.40	18	0.55		0.48
<u>Ataxic</u>					<u>0.14</u>	
Diplegic	1	0.03	2	0.06		0.05
Congenital (simple)	3	0.09	2	0.06		0.08
Dysequilibrium	1	0.03	0			0.02
<u>Dyskinetic</u>					<u>0.37</u>	
Athetotic	6	0.19	7	0.21		0.20
Dystonic (tonuschanging)	1	0.03	4	0.12		0.09
Dystonic + Athetotic	3	0.09	3	0.09		0.09
<u>Mixed forms</u>	7	0.22	4	0.12	<u>0.17</u>	
Total	60	1.86	63	1.93		1.90

of whether the motor handicap was severe or not. The pre-dominance of boys was most marked in children with OMH. Among children with CP the differences were small, except in the spastic diplegic group (60% boys).

In the total group of motor handicapped children all with a birth weight of 2 000 grams or less had CP. Of these (n=37) only 43% were boys; making an "inverse" boy/girl ratio in this low birth weight CP group.

Severity of motor handicap

One third of the children had a severe motor handicap (Table 8). There was an equal amount of severely motor

Table 8. Severity of motor disturbances among motor handicapped children in MLL. Percentage

Diagnosis	DEGREE OF MOTOR HANDICAP			
	Slight %	Moderate %	Severe %	Total %
CP n=183	62.8	7.7	29.5	100
SBC n= 24	20.8	12.5	66.7	100
OMH n= 59	50.9	18.6	30.5	100
Total n=266	56.4	10.5	33.1	100

handicapped children born during the early and late half of the period (1960-72).

The children with SBC had the highest rate (two out of three) of severe motor handicap.

All the dystonic and dystonic + athetotic as well as the vast majority (87.5%) of the children with spastic tetraplegic CP were severely motor handicapped (Table 9). The lowest rate of severely motor handicapped among the children with CP was found in those who had a spastic hemiplegia (7.3%).

Intellectual capacity

Three out of four of all the motor handicapped children in MLL had normal (normal + dull) intellectual capacity (Table 10).

The children with CP had the highest rate (one out of three) of mental retardation; one out of four being severely mentally retarded (Table 11). Most children with dystonic (64.7%), mixed (63.6%) and especially spastic tetraplegic (87.5%) forms of CP were severely mentally retarded. On the other hand more than four out of five of the children with athetotic, hemiplegic and diplegic CP had normal (dull included) intellectual capacity.

Table 9. Severely motor handicapped children with CP in MLL.
Number and percentage

CP, type		SEVERELY MOTOR HANDICAPPED	
		n	%
<u>Spastic</u>	<u>n=119</u>	<u>22</u>	<u>18.5</u>
Hemiplegic	n=55	4	7.3
Tetraplegic	n= 8	7	87.5
Diplegic	n=56	11	19.6
<u>Ataxic</u>	<u>n= 19</u>	<u>4</u>	<u>21.1</u>
<u>Dyskinetic</u>	<u>n= 34</u>	<u>21</u>	<u>61.8</u>
Athetotic	n=17	4	23.5
Dystonic (tonus changing)	n= 7	7	100
Dystonic+ athetotic	n=10	10	100
<u>Mixed forms</u>	<u>n= 11</u>	<u>7</u>	<u>63.6</u>
Total	n=183	54	29.5

Table 10. Intellectual capacity of motor handicapped children in MLL. Percentage

Diagnosis	INTELLECTUAL CAPACITY (%IQ)				
	Normal (>90) %	Dull (70-90) %	Mildly (50-69) retarded %	Severely (<50) retarded %	Total %
CP n=183	50.3	18.6	6.5	24.6	100
SBC n= 24	66.7	16.7	4.1	12.5	100
OMH n= 59	69.5	16.9	8.5	5.1	100
Total n=266	56.0	18.0	6.8	19.2	100

Table 11. Intellectual capacity among children with CP in MLL. Percentage

CP, type	INTELLECTUAL CAPACITY (~IQ)					Total
	Normal (>90) %	Dull (70-90) %	Mildly retarded %	Severely retarded %		
<u>Spastic</u> <u>n=119</u>						
<u>Hemiplegic</u>		60.5	17.6	5.9	16.0	100
Tetraplegic	n=55	69.1	14.5	5.5	10.9	100
Diplegic	n=8	0	12.5	0	87.5	100
	n=56	60.7	21.4	7.2	10.7	100
<u>Ataxic</u> <u>n= 19</u>		31.6	21.1	10.5	36.5	100
<u>Dyskinetic</u> <u>n= 34</u>		38.2	17.7	8.8	35.3	100
Athetotic	n=17	70.6	17.6	5.9	5.9	100
Dystonic (dysto- nic & athetotic)	n=17	5.9	17.6	11.8	64.7	100
<u>Mixed forms</u> <u>n= 11</u>		9.1	27.3	0	63.6	100
<u>Total</u> <u>n=183</u>		50.3	18.6	6.5	24.6	100

DISCUSSION

WITH SPECIAL REFERENCE TO THE 1966 MLL STUDY

The present (1976) study is comparable with that of 1966 (10, 25) because the same age groups of motor handicapped children have been investigated in the same area by the same investigator using the same system of classification. Distribution on age was also very similar. The reason for excluding children under 4 years of age is that a rising number of handicapped children are diagnosed during the first 4 years of life (43). However, at 4 years of age all major handicaps are known and diagnosed (40).

In 1976 as well as in 1966 (n=194. MLL 0.4 million inhabitants; 18% 4-16 years of age) 0.3% of children 4-16 years of age in MLL had a motor handicap, most often due to CP (69% vs. 66%). The proportions of different types of CP were similar and agree well with the findings of other Swedish surveys (3, 4, 16).

In Denmark Glenting found that the incidence of CP was about 2.6 per 1 000 in the 1950s and about 2 per 1 000 in the 1960s (5). The incidence of CP in MLL (1.9 per 1 000) is unchanged throughout the years of the present study and close to what was found 10 years earlier (1.8 per 1 000). Thus, no significant change in the incidence of CP in MLL was found for a 20-year-period. However, in the first study (25) the incidence of CP would probably have been somewhat higher if more of the severely mentally retarded

children at special institutions had been investigated in search for associated motor disabilities. This leaves a possibility of a slight "hidden" reduction of the real CP incidence between the two studies. The incidence of CP in MLL is similar to that in several other reports (3, 6, 7, 8, 9); and is not significantly different from that of Hagberg et al. (15, 17). They found a decrease of CP incidence especially among spastic/ataxic diplegia and low birth weight children 1954-70, followed by a tendency to increase of diplegia in the 1970s (18). There was no significant difference concerning rate of diplegia in the present study compared to the 1966 one (30% vs. 26% of the children with CP). The incidence of diplegia was the same for the 5-year-period 1963-67 as for the period 1968-72. However, as seen in Fig. 2 there is a possible trend during the 1960s of decreasing frequency of diplegia, followed by an increase in the very end of that decade and the beginning of the next. This trend is in agreement with the observations by Hagberg (18).

Recent figures from Australia show a rise in CP incidence in the late 1960s followed by a fall in the 1970s. Improvement in outcome was more marked in the heavier infants than in those of low birth weight (45).

There is a highly significant ($p < 0.001$) increase in the number of children with SBC in MLL between the 1966 and 1976 series ($n = 2$ vs. 24) due to the active treatment

without selection of the children with SBC since the mid 1960s.

The incidence of live born SBC (0.6 per 1 000) was the same as that found in a recent survey from all southern Sweden (21) and close to what was earlier reported (0.7 per 1 000) by Hagberg et al. (46).

Since the 1950s there has been no epidemic of poliomyelitis in Sweden. The 2 children with sequel to poliomyelitis were adopted from Asia. They had had polio before coming to Sweden.

In both the MLL studies boys outnumbered girls. In the CP group this was most marked among the spastic diplegic children. In the present study an "inverse" boy/girl ratio was observed in the low birth weight (2 000 gr or less) CP children. This is almost certainly due to higher early neonatal death rate in low birth weight boys than in girls (33, 47, 48). The low rate of boys among low birth weight CP children and the dominance of boys in the more maturely born children with CP is in agreement with the often quoted statement that boys are on the whole more vulnerable in the neonatal period than girls. The recessive, X-linked inheritance in muscular dystrophy (Duchenne) is of main importance for the excess of boys in the OMH group.

In the present study more children were severely motor handicapped than in the 1966 one (33% vs. 22%). However,

there are no changes in the ratio of severely motor handicapped throughout the years in the present study. Of greatest importance for the difference in the amount of severely motor handicapped children between the two studies is the higher number of dystonic, dystonic + athetotic and mixed forms of CP in the latter study (50% vs. 32%/1966). Looking only at the spastic CP children the amount of severely motor handicapped is unchanged (18% vs. 17%).

The mortality in SBC children has decreased dramatically during the 1960s. Thus, the higher number of SBC children - with a high rate (66.7%) of severe motor handicap - in the latter study has contributed to the total rise of severely motor handicapped.

The ratio of mentally retarded is exactly the same in the two investigations. However, among the mentally retarded a greater proportion had a severe mental handicap in the latter study ($p < 0.01$). The shift is mainly due to changes among the children with CP ($p < 0.001$).

There were more people moving in than out of the county - since the late 1960s especially from the adjacent city of Malmö. This was true also for families with motor handicapped children. One of the reasons for moving from Malmö (with very good habilitation facilities) to the MLL area is greater possibilities here to acquire a dwelling with direct ground level access - which means a lot for families

with handicapped children. The motor handicapped children coming from Malmö had a slightly lower frequency of severe motor and severe mental handicaps than the others in the study. Thus, more handicapped children moving in than out of the county have not contributed to the relative increase of severely motor and severely mentally retarded motor handicapped children in the county.

The increase of severely motor and mentally handicapped children may be related to the fact that this study is complete even with respect to the severely mentally retarded children with motor handicaps. There are also other possibilities to consider. Throughout the years the efficiency of the neonatal intensive care has increased. This has lowered the neonatal mortality, more in MLL than nationally (48, 49) and may thus have implied early and very active resuscitation of a number of severely brain injured newborns. Among children who formerly should have died some may have survived with brain damage resulting in severe motor handicap and severe mental retardation. Similar explanations have been suggested in other recent studies (18, 50, 51) and are further discussed in Chapter III.

CHAPTER II

ASSOCIATED HANDICAPS, ACTIVITIES IN DAILY LIVING (ADL) AND TOTAL HANDICAPS IN MOTOR HANDI- CAPPED CHILDREN

Many motor handicapped children have one or more associated handicaps which aggravates their difficulties and make their total handicap situation a more serious one (10, 52). Usually, this is not sufficiently considered.

The aim of this chapter is to give an account of associated handicaps, their frequency of occurrence, distribution and degree as well as their importance for the total handicap situation.

Associated handicaps

The vast majority of children with CP (82%) and SBC (95.8%) and a little more than half of them with OMH (55.9%) had associated handicaps (Table 12). About 60% of the children with CP (63.4%) and SBC (58.3%) and only 27.1% of the children with OMH had two or more associated handicaps.

Table 12. Associated handicaps in motor handicapped children in MLL. Percentage

Diagnosis	ASSOCIATED HANDICAPS			Total %
	One	Two	Three or more	
	%	%	%	
CP n=183	18.6	21.3	42.1	82.0
SBC n= 24	37.5	20.8	37.5	95.8
OMH n= 59	28.8	11.9	15.2	55.9
Total n=266	22.5	19.2	35.7	77.4

The distribution of associated handicaps is shown in Fig. 3.

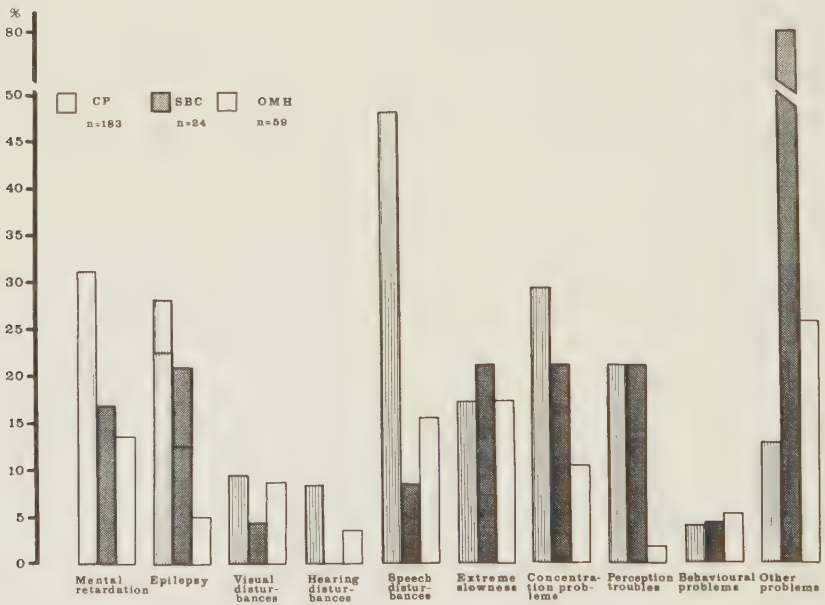


Fig. 3. The distribution of associated handicaps for motor handicapped children in MLL. Percentage (Epilepsy: above line = no convulsions during the last 2 years)

Mental retardation

In Sweden mentally retarded children are guaranteed free tuition and care by the County Council Board for Provisions and Services to the Mentally Retarded (53). In the present investigation all but 5 (93%) of the mentally retarded children (n=69) were under such care. All 5 were of preschool age.

Mental retardation was common (26.0%); especially common in children with CP (31.1% of which 24.6% were severely mentally retarded). Least often mentally retarded among children with CP were those who had athetotic (11.8%), hemiplegic (16.4%) and diplegic (17.9%) forms. Most children with spastic tetraplegic (87.5%), dystonic (64.7%) or mixed forms (63.6%) of CP were severely mentally retarded. (See also Chapter I, Intellectual capacity, Table 10 and 11).

Seizures and epilepsy

About one third (32.3%) of the motor handicapped children had (at least once) had seizures, most often the children with CP (40.4%) and least often the children with OMH (6.8%) (Table 13).

Table 13. Seizures and epilepsy in motor handicapped children in MLL. Percentage

Diagnosis	SEIZURES					EPILEPSY		Total
	Total	In the newborn period only	Later but not during the last 2 years	During the last 2 years	Without seizures during the last 2 years, most likely due to antiepileptic treatment			
	%	%	%	%	%	%		
CP n=183	40.4	3.8	14.2	22.4	5.5	27.9		
SBC n= 24	33.3	0	20.8	12.5	8.3	20.8		
OMH n= 59	6.8	0	1.7	5.1	0	5.1		
Total n=266	32.3	2.6	12.0	17.7	4.5	22.2		

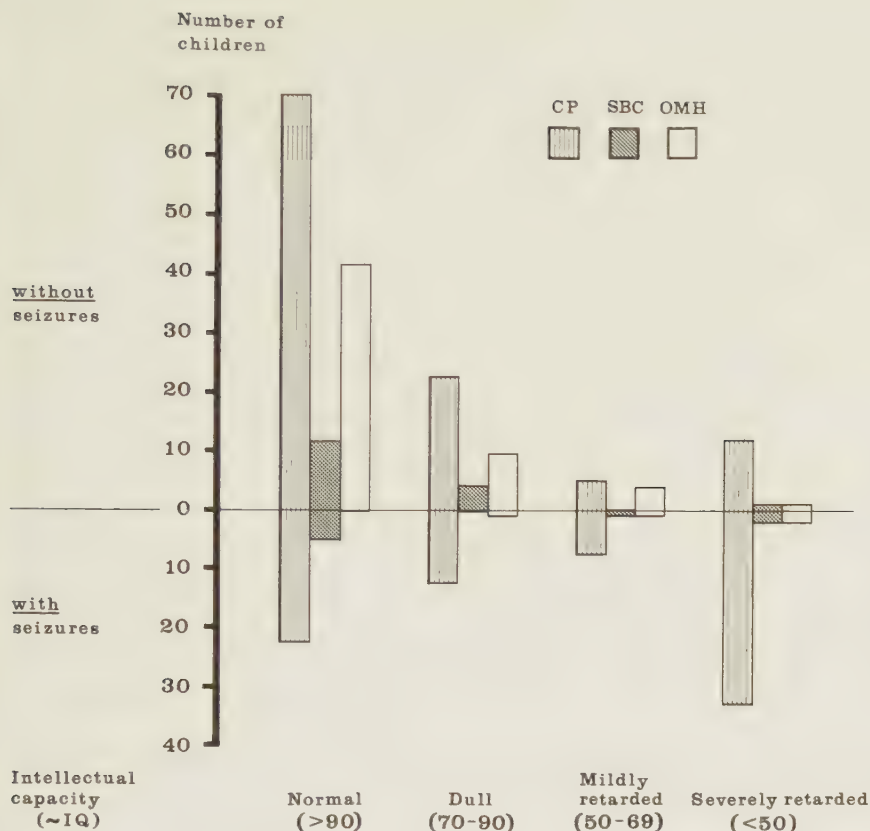


Fig. 4. Seizures related to intellectual capacity

A little more than one fifth (22.2%) of the motor handicapped children had epilepsy; 27.9% of the children with CP, 20.1% with SBC and only 5.1% of those with OMH. Far more of the severely than the slightly or moderately motor handicapped children had had seizures or had epilepsy ($p < 0.001$). A close correlation ($p < 0.001$) was also found between seizures and mental retardation (Fig. 4), as between mental retardation and epilepsy (Table 14). Epilepsy was four times more common among mentally retarded children with CP (57.9%) - nearly five times among

Table 14. Epilepsy in relation to diagnosis and intellectual capacity in motor handicapped children in MLL. Number and percentage

Diagnosis	EPILEPSY /All (of each group)					
	INTELLECTUAL CAPACITY (~ IQ)					
	Normal (>90)	Dull (70-90)	Mildly retarded (50-69)	Severely (<50) retarded	Total	
	n %	n %	n %	n %	n	%
CP n=183	13/92 14.1	5/34 14.7	3/12 25.0	30/45 66.7	51/183	27.9
SBC n= 24	2/16 12.5	0/4 0	1/1 100	2/3 66.7	5/24	20.8
GMH n= 59	0/41 0	1/10 10.0	0/5 0	2/3 66.7	3/59	5.1
Total n=266	15/149 10.1	6/48 12.5	4/18 22.2	34/51 66.7	55/266	20.8

severely mentally retarded (66.7%) compared to the intellectually normal (dull included) ones (14.3%).

Antiepileptic drugs were considered unnecessary for 6 of the epileptic children (n=59; CP 51, SBC 5 and OMH 3). Five of the 53 children taking antiepileptic drugs had a severe associated handicap due to unsatisfactorily controlled epilepsy (convulsions roughly once a week or more). Of the remaining drug treated epileptic children (n=48) 12 had had no seizures for 2 years or more.

Table 15 gives the types of seizures for the CP group. Grand mal was by far the most frequent type. Minor motor fits were found only among children with CP, most often in combination with grand mal.

Table 15. Types of seizures among children with CP in MLL

Seizure ^{a)} , type	Total n	One type only n	Combina- tions n
Psycho motor	4	1	3
Grand mal	64	47	14
Minor motor	16	2	
Total n	67	50	17

a) All CP children with seizures (epilepsy or not) except those (seven) who had seizures in the newborn period only

One child with OMH had grand mal in combination with psychomotor epilepsy. The other 3 with OMH and all the 8 with SBC - with epilepsy - had only had grand mal.

Visual disturbances

Visual disturbances were noted in 9% of the children, with severe disturbances occurring in 5%. Out of widely varying reasons one fourth (24.1%) of the motor handicapped children were prescribed glasses; children with SBC most frequently (37.5%).

Hearing disabilities

None of the children with SBC and only 2 with OMH had hearing disabilities. Among the children with CP 8.2% had hearing impairment; 6% being severe.

Speech disabilities

One third of the intellectually normal and half of the mentally retarded children, in all 36.8% (98 children) had speech disabilities - 16% (43 children) having no useful talk at all.

The children with CP had the greatest rate of speech problems, 41%; 22% (40 children) lacking speech abilities. Out of these 40 children 37 had a severe motor handicap. Most (29/37) were also severely mentally retarded. Three of the children with CP lacking speech abilities had

neither a severe motor handicap nor a severe mental retardation.

Only 2 of the children with SBC and 9 with OMH had obvious speech problems.

Extreme slowness

Extreme slowness, affecting education, was noted in 17%, with only slight difference between children with CP, SBC or OMH. Most of these children (43/45) had normal intellectual capacity (dull included) and 2 were mildly mentally retarded.

Concentration problems

Every third child with CP, every fourth with SBC and every tenth with OMH had obvious problems with their concentration.

Perception troubles

Every fifth child with CP or SBC had varified perception troubles, and only 1 of the children with OMH.

Behavioural problems

Eleven motor handicapped children (CP 7, SBC 1 and OMH 3) had evident behavioural problems. Most of them had severely disturbed social relations, often with outbursts

of aggression. Some showed depressive or schizoid features; all had urgent need of psychologic and/or psychiatric help.

Other problems

In other problems (Fig. 3) there were 4 children (CP 2) having an extremely bad (short term) memory, 4 (CP 3) with intense anxiety and uncertainty. Nine of the children with CP and 2 others had severe dribbling. Obesity of very high degree was found in 6 children (CP 3). Two children (CP 1) had a severe VOC. Two of the children with SBC had severe pressure ulcers. Four out of five of the children with SBC were incontinent; one fifth had more severe urinary troubles with impaired kidney functions and often had had diversion operations done. None of the children with CP had moderate or severe urinary troubles. Three of the children with OMH had agenesis of the lower sacral segments and had incontinence without kidney distress.

Activities in Daily Living (ADL)

Of the motor handicapped children in MLL 43.6% were able to manage all their activities in daily living; i. e. were ADL-independent (Table 16). On the other hand, 12.0% were totally dependent on help from another person in ADL respects.

Table 16. Activities in Daily Living among motor handicapped children in MLL. Percentage

Diagnosis	ADL				Total %
	Inde- pendent %	Slightly dependent %	Moderately dependent %	Totally dependent %	
CP n=183	45.4	23.5	14.7	16.4	100
SBC n= 24	8.3	50.0	41.7	0	100
OMH n= 59	52.5	18.7	25.4	3.4	100
Total n=266	43.6	24.8	19.6	12.0	100

More than twice as many schoolchildren (~7 years or more) were independent compared to the preschoolchildren (54% vs. 21%; $p < 0.001$). Of the older children (10 years or more) 58% were ADL-independent; the same applied to only 28% of those under 10 years of age.

Among the children with CP the spastic hemiplegic and diplegic ones were most often ADL-independent (61.3%). A good 40% of the athetotic and atactic children were also independent. Not one child with spastic tetraplegic or dystonic or mixed forms of CP was ADL-independent.

Only 2 of the children with SBC were independent but, on the other hand, none was totally ADL-dependent.

The figures concerning ADL are in Table 17 compared to those in the 1966 series.

Table 17. ADL-dependency in the 1966 and 1976 study of
of motor handicapped children in MLL. Percentage

Diagnosis	ADL-DEPENDENCY			Total %
	None	Slight - moderate	Total dependency	
	%	%	%	
	1966 → 1976	1966 → 1976	1966 → 1976	
All motor handicapped n=194 → 266	47 → 44	36 → 44	17 → 12	100
Of which CP n=128 → 183	48 → 45	33 → 38	19 → 17	100

Total handicap

While roughly 40% of the children with CP or OMH had a severe total handicap this was true for as many as 70.8% of the children with SBC ($p < 0.005$). The degree of motor and total handicap is compared for each diagnostic group in Table 18. One third (88 children) had a severe motor handicap. The total handicap was severe for another 27 children - due to severe associated handicaps. Thus, a total of 43.2% (115 children) had a severe total handicap. The motor handicap was moderate for 10.5% and the total handicap was moderate for as many as 32.0% of the motor handicapped children.

Table 18. Severity of motor and total handicap among motor handicapped children in MLL. Percentage

Diagnosis	DEGREE OF MOTOR AND TOTAL HANDICAP				
	Slight	Moderate		Severe	Total
	% motor → total	% motor	% total	% motor → total	%
CP n=183	62.8 → 28.4	7.7 → 30.1		29.5 → 41.5	100
SBC n= 24	20.8 → 8.4	12.5 → 20.8		66.7 → 70.8	100
OMH n= 59	50.9 → 20.3	18.6 → 42.4		30.5 → 37.3	100
Total n=266	56.4 → 24.8	10.5 → 32.0		33.1 → 43.2	100

Of those children who had multiple reasons for being classified as severely totally handicapped (53 children), all but one (with CP) had a severe motor handicap (Table 19).

Most of the 76 CP children with a severe total handicap had multiple reasons for this. The majority had a severe motor handicap (54/76; 71.7%) and/or a severe mental retardation (45/76; 59.2%).

The most frequent reason for classifying the children with SBC and OMH as being severely totally handicapped was a severe motor handicap only.

Total ADL-dependency was never the only reason for a motor handicapped child to be assigned as severely totally handicapped. They were all classified as that already by their severe motor and/or severe mental and/or severe other associated handicaps.

Table 19. Reason for classification as severe total handicap in motor handicapped children in MLL. Percentage

Diagnosis	REASON FOR CLASSIFICATION				Total
	Severe motor handicap (only) %	Severe mental retardation (only) %	Other severe associated handicap (only) %	Multiple reasons %	
CP n= 76	17.1	13.1	14.5	55.3	100
SBC n= 17	58.8	0	5.9	35.3	100
OMH n= 22	59.1	4.6	13.6	22.7	100
Total n=115	31.3	9.6	13.0	46.1	100

DISCUSSION

WITH SPECIAL REFERENCE TO THE 1966 MLL STUDY

There are obvious similarities between the 1966 and 1976 studies. The majority of children with CP had one or more associated handicaps (64% vs. 82%). Two or more associated handicaps were noted in a high proportion of children with CP or SBC, especially in the present study. The increase is likely to reflect more children now being multiple handicapped, but may also to some extent be due to more complete registration.

Mental retardation

Mental retardation was equally common. However, the frequency of severe mental retardation was higher in the latter series (p. 38).

In children with CP the rate of seizures during the last two years was also similar in the two studies (20% vs. 22.4%). The rate of epilepsy in the present study (27.8%) among children with CP is somewhat higher than that found by Hansen (22.2%) (7), but similar to what has been reported by others (3, 9). Foley found that 12% of his athetoid children had epilepsy, in the other CP diagnostic groups about 50% had epilepsy. In his study the frequency of epilepsy seems to be directly correlated to low intelligence in children with CP (with IQ above 40) (54). In the present study epilepsy was strongly corre-

lated to mental retardation and likewise to the severity of the motor handicap. A little more than one fifth of the children with SBC had epilepsy, confirming the findings of Hosking (55) and Blaauw (56).

The frequency of visual disturbances was similar in the two MLL studies. For children with CP the rate was about one of ten. If also minor eye abnormalities such as strabism and slight refraction errors had been included, the estimates of this study might possibly have reached the higher values (strabism 40%; refraction errors 43%) reported by Pearlstone (57). In Denmark Glenting found visual disturbances in 49% of congenital spastic CP; 12% with deficient vision (58).

The rate of recorded hearing disabilities was similar in the two MLL studies. The figures concerning children with CP are well within those given by Robinson for definite (3.8%) and possible (12.5%) auditory deficiency in a selected group of children with CP (59).

The rate of speech problems among children with CP was high in both MLL studies. In this second one speech disabilities were the most frequent associated handicap in CP (47.5%). This is close to the rate reported by Ingram (9). Among children with CP examined by a specialist, Hansen found half to have speech disturbances (7). The higher rate of speech disabilities in the present study compared to the 1966 one is thought mainly to reflect the

larger proportion of severely motor and severely mentally handicapped children in this series. Improved diagnostics may also have contributed to the difference.

Improved diagnostics are likely to be the main reason for the higher rate of extreme slowness, concentration, perception and behavioural problems noted in 1976 compared to 1966. These problems might be somewhat more frequent than noted in the present study because no systematic psychological study was done. Still, the figures are of great interest, representing the amount of motor handicapped children in urgent need of help because of their associated handicaps.

The two surveys are similar in ADL respects. In the material as a whole, as well as among children with CP, it is remarkable that there are not more totally dependent children in this study, considering more children were severely motor and severely mentally handicapped. This is likely to reflect a better ADL-training nowadays than earlier. More of the younger than the older motor handicapped children are ADL-dependent. The difference between the two groups is likely to diminish with time. More of the young, dependent, motor handicapped children of today may in the future - through development and training - become ADL-independent.

CHAPTER III

FAMILY AND DELIVERY CONDITIONS

WITH SPECIAL REFERENCES TO FACTORS OF POSSIBLE
ETIOLOGICAL IMPORTANCE FOR CP

In 1862 William John Little published ingenious observations and thoughts about CP and its cause in his classical: "On the influence of abnormal parturition, difficult labours, premature birth, and asphyxia neonatorum, on the mental and physical condition of the child, especially in relation to deformities" (28). Since then etiological factors in CP have been discussed in numerous studies (7, 9, 10, 15, 17, 32, 33, 50).

In this chapter some family and delivery circumstances among motor handicapped children will be elucidated, especially factors of possible etiological importance for CP.

Socio-economic grouping

In this respect one multihandicapped girl with CP in an institution for severely mentally retarded is excluded because she had no relatives in Sweden.

The socio-economic distribution of the motor handicapped children in MLL is in agreement with that for Sweden in general (60) (Table 20). Socio-economic grouping related to diagnosis, degree of motor handicap and intellectual

Table 20. Socio-economic distribution of motor handicapped children according to diagnosis, degree of motor handicap and intellectual capacity in MLL and Sweden generally. Percentage

	SOCIO-ECONOMIC GROUPING			Total
	I %	II %	III %	%
DIAGNOSIS				
CP n=182	14.8	33.0	52.2	100
SBC n= 24	8.4	33.3	58.3	100
OMH n= 59	13.6	37.3	49.1	100
Total n=265	14.0	34.0	52.0	100
DEGREE OF MOTOR HANDICAP				
Slight-moderate n=178	15.7	36.5	47.8	100
Severe n= 87	10.4	28.7	60.9	100
INTELLECTUAL CAPACITY				
Normal-dull n=197	16.2	36.6	47.2	100
Mentally retarded n= 68	7.3	26.5	66.2	100
SWEDEN Generally (60)	8.3	35.9	55.8	100

capacity is shown in the same table. No correlation was found between type of motor handicap and social group. However, motor handicapped children coming from social group III were mentally retarded and had severe motor handicaps significantly ($p < 0.01$ and $p < 0.05$, respectively) more often than the others. Children with CP weighing 2 500 g or less were socio-economically distributed in the same way as the rest of the motor handicapped children.

Age of parents

The age of the mothers and the fathers at delivery of the motor handicapped child is shown in Fig. 5. Also a cumulative index is given for the mothers in the series compared to Swedish mothers in general (42). The figures are very close. (There are no general figures available to compare with the age of the fathers.)

Number of children

Forty per cent of the child families in MLL as well as in all Sweden had two children in 1976 (42). This also applied to the MLL families with a motor handicapped child. In these families the mean number of children per family was 2.5; the average for all child families in Sweden being 1.9 (42).

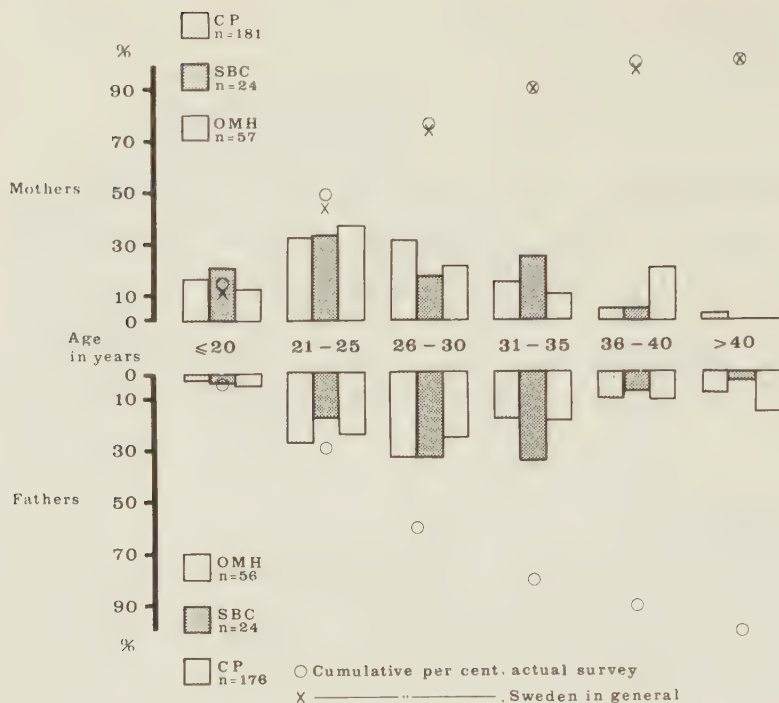


Fig. 5. Age distribution of mothers and fathers of motor handicapped children in MLL (at the time of the child's birth)

First born

In Sweden about half of all children are first born (42). Forty-six per cent of the motor handicapped children - 51% of the children with CP - were first born. Thus, there was no excess of first born in the present study. Neither was there found any correlation between the child being first born and the degree of motor, mental or total handicap.

Only child

About 45% of MLL and all Swedish child families only have one child (42). The motor handicapped child in MLL was not often (15%) the only child in the family. There was no preponderance of severe motor or severe total handicaps in the only (motor handicapped) child.

Latest child

The motor handicapped child in 49% had no younger sibling. The majority of families with children with CP or SBC (53% and 54%, respectively) did have another child after the handicapped one. The opposite was true for children with OMH where only 44% had a younger sibling. When the motor handicapped child was the latest he/she was not more often severely motor or severely totally handicapped than the other children in the study.

Twins

In the present study 21 children - all having CP - were born in 20 pairs of twins. Thus, the frequency of twins (11.5%) was highly significantly increased ($p < 0.001$) among the children with CP compared to the average for Sweden (1.6%) (42). Twin deliveries were ten times that for Swedish children in general (1/85) (42). More of the twins with CP were second than first born (12 vs. 9). There was also a slight preponderance of second born twins among those who in these 20 pairs had died (Fig. 6).

Percentage of
twins (n=20)

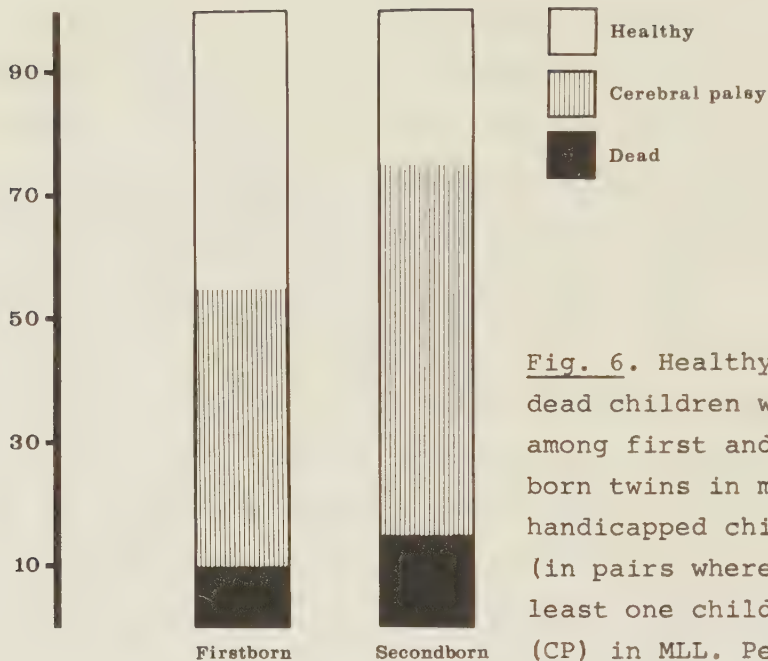


Fig. 6. Healthy and dead children with CP among first and second born twins in motor handicapped children (in pairs where at least one child has (CP) in MLL. Percentage

Place of delivery

Place of delivery is unknown for 3 children (2 with polio and 1 with muscular dystrophy) born outside Sweden. One boy with muscular dystrophy was born at home, another with SBC at a small delivery unit outside hospital. This means that all the 183 children with CP and 97.5% of the others were delivered in hospitals, nearly 70% at maternity hospitals, 30% at county hospitals without a special obstetric department. The ratio of maternity/county hospital deliveries was the same in this series as for the county in general (during the same time period). The rate of

severely motor handicapped was the same in children with CP born at maternity compared to county hospitals.

Artificial delivery

Vaccum extraction was twice, forceps three times, more often used in the children with CP in the study compared to the average (2.9% and 0.6%, respectively) for Lund's University Maternity Hospital (1961-72) (61).

Twelve of the motor handicapped children had been delivered by caesarean section, 11 later showing signs of CP, 1 having his motor handicap caused by a traffic accident. The indications for caesarean section were: diabetes in the mother (four), anatomical reasons (four), ablatio placentae (two) and renovascular hypertension (one). In 4 children intra- and/or extrauterine asphyxia was recorded.

Presentation

The presentation is unknown for 8 motor handicapped children. Of the vaginally delivered 9.4% of the children with CP, 7.3% with OMH and as much as 26.1% with SBC were presented by breech (Table 21). These figures are all high compared to the expected one (3%) (61, 62).

Table 21. Vaginal deliveries and caesarean section of motor handicapped children in MLL. Percentage

Diagnosis	VAGINAL DELIVERIES			CAESAREAN	Total
	Vertex, normal %	Vertex, abnormal %	Breech %	SECTION %	%
CP n=180	80.6	3.9	9.4	6.1	100
SBC n= 23	73.9	0	26.1	0	100
OMH n= 55	83.6	7.3	7.3	1.8	100
Total n=258	80.6	4.3	10.5	4.6	100
Lund University Maternity Hospital General percentage 1961-72 (61)	90	4	3	3	100

Birth weight

Number of children by birth weight is shown for spastic diplegia (separately), other CP (than spastic diplegia) and other diagnoses (SBC + OMH) in Fig. 7. Just 1 child with SBC and 1 child with OMH had a birth weight of 2 500 g or less, none weighed 2 000 g or less.

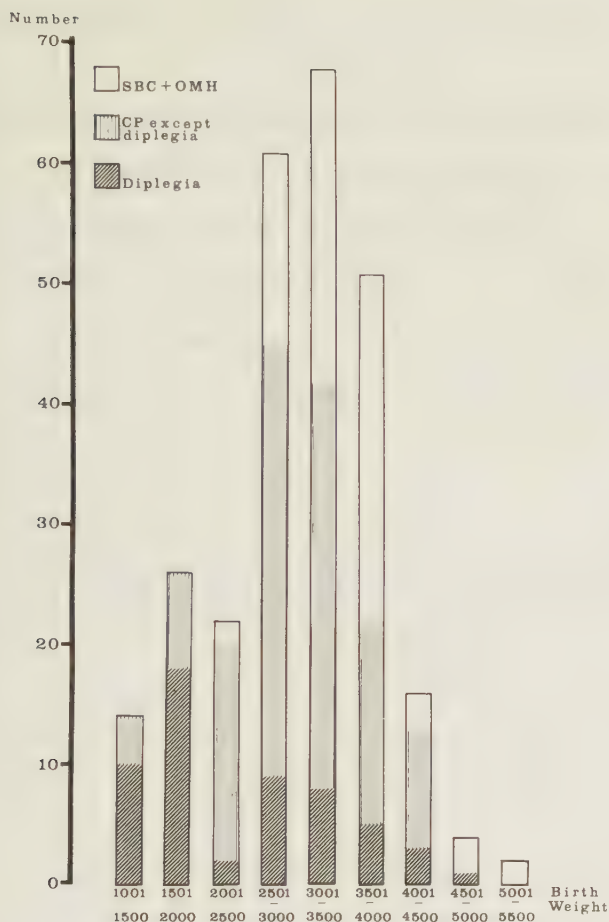


Fig. 7. Number of children per birth weight for diplegia (separately), other CP and SBC + OMH in MLL

One third of the children with CP - 54% of the spastic diplegics, 24% of the others - had a birth weight of 2 500 g or less. Half of the 56 spastic diplegic children and 9.5% of the other 126 children with CP had a birth weight of 2 000 g or less. Thus, there was a preponderance of low birth weight among the children with CP - especially birth weight of 2 000 g or less among the spastic diplegics.

Week of gestation at birth

Seventeen of the motor handicapped children - all having CP - were born in gestational week 28-31. Most of them (76.5%) had a spastic diplegia. As can be seen from Table 22, 53.6% (30/56) of the spastic diplegics, 17.5% (22/126) of the other children with CP and only 3.8% (3/80) with SBC + OMH were born in 36th week of gestation or earlier.

Table 22. Number of spastic diplegia, other CP and SBC+OMH in regard to birth weight and gestational age

Gesta- tional age	Diagnosis	BIRTH WEIGHT		Total n
		≤ 2 500 g n	> 2 500 g n	
≤ 36 week	Diplegia	28	2	30
	Other CP	17	5	22
	SBC+OMH	1	2	3
> 36 week	Diplegia	2	24	26
	Other CP	13	91	104
	SBC+OMH	1	76	77
Total	Diplegia	30	26	56
	Other CP	30	96	126
	SBC+OMH	2	78	80

Birth weight/week of gestation

The motor handicapped children weighing 2 500 g or less or being born week 36 or earlier are shown in Fig. 8.

Among the children with CP fullfilling these criteria 62.2% (28/45) had a spastic diplegia.

Weight at birth (kilograms)

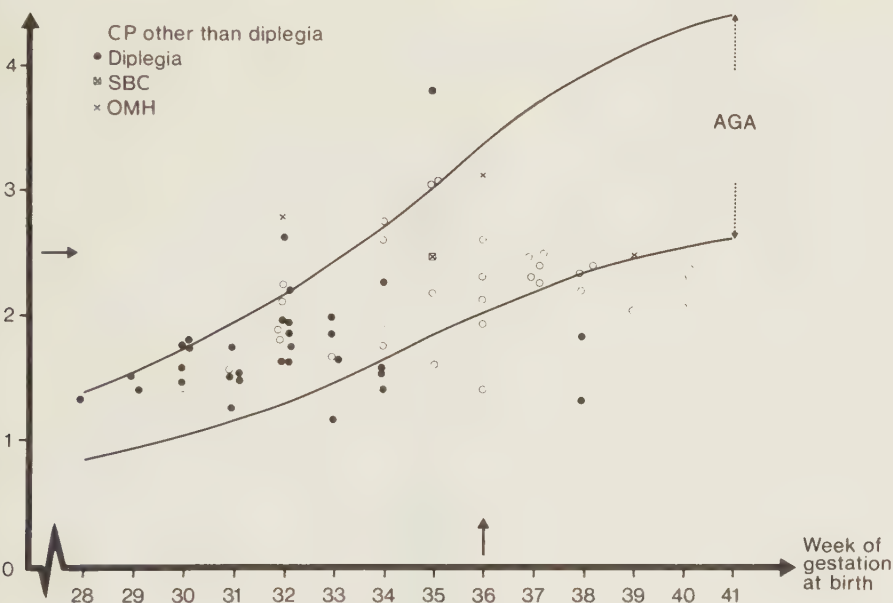


Fig. 8. Weight and week of gestation at birth for motor handicapped children in MLL - born week 36 or earlier or weighing 2 500 g or less. Curves for AGA according to Sterky (41).

Appropriate, light or heavy for gestational age

The vast majority - 84.7% (155/183) of the children with CP, all (24/24) with SBC and 83.9% (47/56) of the OMH children - were born appropriate (AGA) for gestational age (Fig. 9).



Fig. 9. Number of motor handicapped children in MLL being light, appropriate or heavy for gestational age.

The children with CP were light for gestational age in 12.6% (23/183). The dyskinetic CP children had the highest rate (20.6%; 7/34) of lightness for gestational age.

Just one of the children with OMH was born light for gestational age.

Only 2.7% (5/183) of the children with CP, 14.3% (8/56) with OMH were born heavy for gestational age.

Cause of CP

The cause of the brain damage was obvious in 46% and most likely in another 35% of the children with CP. In the remaining 19% the cause was untraceable, the pre-, peri- and postnatal history all being normal.

Prenatal brain injury was to blame in 28.4% (Table 23). Most commonly it was found in the tetraplegic (62.5%), ataxic (57.9%) and mixed forms (45.4%) of CP.

Perinatal brain damage was the most common cause of CP (48.1%), especially to dyskinetic (76.5%) and spastic diplegic forms (64.3%).

The cause was untraceable in the highest rate in the spastic hemiplegic children (32.7%).

Table 23. Etiology of different types of CP in MLL. Percentage

CP, type	PRENATAL %	PERINATAL %	POSTNATAL %	UNTRACEABLE %	Total %
Spastic n=119	24.4	47.0	4.2	24.4	100
Ataxic n=19	57.9	21.1	0	21.0	100
Dyskinetic n=34	20.6	76.5	2.9	0	100
Mixed forms n=11	45.4	18.2	27.3	9.1	100
Total n=183	28.4	48.1	4.9	18.6	100

DISCUSSION

The socio-economic distribution of the families with motor handicapped children was not different from the average for Sweden. These findings are in agreement with earlier reports (4), also from this (MLL) area (10). However, a greater proportion of severely motor handicapped and of mentally retarded children were from social group III. This could indicate that in spite of the slight difference today between social classes in Sweden there are still factors in social group III that may have negative influence on the outcome of the motor and the mental handicap. Glenting states that "socio-economic stress and personality problems might well be implicated in the etiology of CP, especially indirectly by predisposing to prematurity" (33). In the present study there was no excess of prematurely born among the children with CP from social group III.

Preponderance of mothers aged 35 years or more has been found for children with CP by some investigators (3, 7) but has been denied by others (51, 63, 64). In this survey no excess of older mothers was found for children with CP, SBC or OMH.

In 1862 Little reported a preponderance of first borns among children with CP, 25%, which at that time must have been a high figure. Since then excess of first borns among children with CP has been noted (3, 7, 8) or denied (63).

Erik Hansen found in his Danish survey a slight excess of first born among children with CP (7). However, his rate of first born CP children was lower than that of the present study and both are below the average for child families in Sweden. Most parents who had a child with CP or SBC (53% and 54%, respectively) had at least one other child after the handicapped one, while the opposite was true for families with a child with OMH (44%). The difference is not statistically significant but the tendency may be related to knowledge about genetic backgrounds, e.g. in muscular diseases and in malformations; this knowledge forcing some parents to stop having more children. Reduced fertility could also have been of importance. However, in contradiction to this is the relatively high mean number of children (2.5) in the families with motor handicapped children compared to the average for all child families in Sweden (1.9). The real difference may be a little less (than 2.5 vs. 1.9) because motor handicapped children 0-3 years of age are not included in the study.

It has been reported that the second born twin runs the greatest risk of brain damage or death in twin pairs where at least one has CP (33, 65). There is also in this study a tendency towards the second born twin risking the worst fate even if the figures are too small to be statistically significant.

In this study as well as in earlier ones - recently stressed by Stanley (45) - abnormal presentation at delivery is overrepresented among children with CP. This delivery complication is often considered to be of etiological importance for CP.

The excess of breech deliveries (26.1%) in children with SBC is remarkable. It cannot be explained by hydrocephalus, which very few of these children have shown clinical signs of before the second or third week of life. The sele itself - often in the lumbo-sacral region - is not mechanically in favour of breech delivery. Muscular weakness and imbalance may play a role. All children with spinal muscular atrophy (n=8) in this study were born in normal vertex deliveries. This indirectly speaks in favour of local - not generalized - muscular weakness as a reason for the excess of breech deliveries in children with SBC. Certainly of major importance is the fact that the diameter of the breech is smaller - and then also smaller than the vertex - when hip extensors are paralyzed, the muscular mass reduced (atrophic) and the fetus has hips flexed and knees extended. This statement agrees with considerations by Dunn (62).

The correlation between low birth weight and CP - especially spastic diplegia - is in good accordance with other studies (10, 16, 32, 51). Kyllerman found a relatively large number of dyskinetic children being light

for gestational age (66). This finding was confirmed in the present study.

The figures for etiology of CP agree closely with the findings of Hagberg et al. (16) and are also very close to those reported by Cussen et al. (32). This is shown in Table 24. The present study compared to that of 1966 (10) from the same MLL area shows the same rate of perinatal causes of CP. The part played by postnatal causes has decreased (from 11% to 5%). The amount of untraceable causes of CP has markedly decreased (31% vs. 19%). A great increase is found of prenatally injured children with CP

Table 24. Etiology of CP in MLL compared to other investigations. Percentage

Investigation	ETIOLOGY				Total %
	Pre-natal %	Peri-natal %	Post-natal %	Un-traceable %	
MLL-area 1960-72 (present study) n=183	28	48	5	19	100
Gothenburg study 1954-70 (Hagberg et al -75) n=560 (16)	25	48	6	21	100
S.H.B.-area 1966-75 (Cussen et al -79) n=254 (50)	28	51	10	11	100

(6% vs. 28%). Better knowledge and improved diagnostics is thought to be the main explanation for this increase of prenatal (as well as the decrease of untraceable) etiology of CP between the two MLL studies. As early as 1897 Sigmund Freud stated that many children with CP who were said to have acquired their brain damage during delivery could have been injured already prenatally (27). This has recently been stressed (16).

In spite of continuously decreasing perinatal mortality the CP incidence has not increased. In this study - compared to the one made 10 years earlier - more children with CP were found with severe motor handicaps and severe mental retardation. This may indicate that a more intensive neonatal care may for some time have contributed to the increase of severely handicapped children in MLL. This may agree with Davies' (67) theory that intensive neonatal care in the beginning leads to increased rates of handicaps - which later will decrease again. Both benefits and hazards of neonatology are to be considered (68). In recent studies from Lund it has been shown that progress in obstetrics and intensive neonatal care has lowered the incidence of neurodevelopment sequelae in certain risk groups (69). Only a minor part of the children with CP in this study were classified as children at risk. Children at risk, according to traditional criteria also do not develop more handicaps than other children (70).

PART TWO

SOCIO-PAEDIATRIC ASPECTS ON CHILDREN WITH CP OR SBC

- AND THEIR FAMILIES

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INTRODUCTION

The consequences for a child with a motor handicap are related to type and severity. It has an impact on the child's personal and emotional development, educational achievement and social adaptation. It has also an impact on the family. Since handicap is the result of the potentials of the individual and the demands of the surroundings, the living conditions of the child and the resources of society strongly influence the extent of the handicap.

The aim of this part of the investigation is to describe and analyse some of the social factors that are important for the motor handicapped child and its family.

METHODS AND CLINICAL MATERIAL

There were 266 motor handicapped children (4-16 years of age) living in the southernmost county council area of Sweden (MLL) in 1976. Of these children, 183 had cerebral palsy (CP), 24 spina bifida cystica (SBC) and 59 other motor handicaps (OMH).

In this socio-paediatic part of the study only children with CP or SBC were included. The 59 children with OMH had so different etiology of handicap and so varying clinical

picture that they were thought to form two small and special subgroups. Furthermore, limited time and shortage of staff and money made us concentrate on the main groups of children with motor handicaps - CP or SBC.

The parents of 3 children with CP did not wish to participate in this part of the investigation. Also, for psychological reasons, no interviews were made with the parents of another 6 children with CP and 1 with SBC, all living in institutions and having no parental contact. Thus, of the 207 children with CP or SBC - with a drop-out of 4.8% - 197 children (CP 174; SBC 23) were investigated with special reference to socio-paediatric circumstances.

The interviewed group (n=197) had roughly the same rate of severe motor handicap, mental retardation, ADL-dependency and total handicap (Table 25), as had the total material (n=266).

Semi-structured interviews were conducted with caregiving parents, i.e. biological, adoptive or foster parents of these children. The interview was performed at home visits by a habilitation social worker.

Table 25. Motor handicap, intellectual capacity, ADL-dependency and total handicap among children with CP or SBC in MLL. Percentage

	MOTOR HANDICAP			INTELLECTUAL CAPACITY				ADL-DEPENDENCY			TOTAL HANDICAP			
	Slight	Moderate	Severe	Normal	Dull	Mildly retarded	Severely retarded	None	Slight	Mode-rate	Total	Slight	Moderate	Severe
	%	%	%	%	%	%	%	%	%	%	%	%	%	%
CP n=174	64.9	8.1	27.0	51.7	19.6	6.3	22.4	47.1	23.6	14.9	14.4	29.3	32.2	38.5
SBC n= 23	21.7	13.1	65.2	69.6	17.4	4.3	8.7	8.7	47.8	43.5	0	8.7	21.7	69.6
Total n=197	59.9	8.6	31.5	53.8	19.3	6.1	20.8	42.6	26.4	18.3	12.7	26.9	31.0	42.1

CHAPTER IV

PARENTS OF CHILDREN WITH CP OR SBC

Having a child with a motor handicap has an impact on the whole family. A child with CP or SBC often means heavy demands especially on the mother, nevertheless, most of these children are cared for at home.

Care and place of residence

Of the 207 children with CP or SBC (including children whose parents were not interviewed) the vast majority (87.9%) were living in private homes. Twenty-five (CP 24; SBC 1) children were cared for in institutions (Table 26). Of these children two thirds were primarily placed in institutions - none of them after 1971.

Table 26. Place of residence and care of all children
(4-16 years) with CP (n=183) or SBC (n=24)
in MLL. Number (and percentage)

	AT HOME (87.9%)			IN INSTITUTION (12.1%) for			Total
	Family home	Adoptive home	Foster home	Severely mentally retarded	Motor handi-capped	Hearing disabled motor handi-capped	
CP	149 ^a	7	5	19 ^b	2	1	183
SBC	20	0	1	0	3 ^b	0	24
Total n	169	7	6	19	5	1	207
(%)	81.6	3.4	2.9	9.2	2.4	0.5	100)

^aThree parents of CP children did not wish to participate in interview part of the study

^bThe parents of 6 CP children and 1 SBC child had no contact with their children and were not interviewed

Parents' contact with their children in institutions

The parental contact with the children cared for in institutions (n=25) was regular and close in 64%, some of these children even staying temporarily at home on weekends and holidays. In 8% the parents made formal visits to the institutions a few times a year. Seven (28%) of the children cared for in institutions had no contact with their parents at all.

Foster and adoptive homes

Of the 174 children with CP, 5 were living in foster homes and 7 were adopted. One of the 23 children with SBC was living in a foster home, none was adopted. The rate of 3% foster children in this study compares with the average of 0.6% in the MLL area (42). For adoption rate (3.5%) there are no comparable statistical figures for the area.

Half (7/13) of the foster and adopted children had come to their present family before they were one year old. Of the 6 foster children, 1 came to her foster family (grandparents) at 2 years of age, another at 3 years of age (after being cared for in a paediatric clinic for SBC) and another at 10 years of age because of social problems in the biological family.

None (0/13) had changed from one foster/adoptive family to another.

All the 7 adopted children and half (3/6) of the foster children did not have a severe motor or a severe total handicap. The other 3 foster children were severely motor handicapped - of which 2 were also severely mentally retarded. These 3 children were all cared for by near relatives, 2 by grand-parents (of unmarried mothers) and 1 by a sister of her mother (who had died at delivery).

Marital status

The marital status in regard to care-giving parents for children with CP or SBC is shown in Table 27. Most parents

Table 27. Civil status of care-giving parents of children with CP or SBC in MLL

NUCLEAR FAMILIES n=176 (89.3%)			INCOMPLETE HOMES n=21 (10.7%)					
Mother + father			Mother alone (8.6%)				Father alone (2.1%)	
Married Cohabitated			Widow	Divorced	Judicially separated	Unmarried	Widower	Divorced
n	n		n	n	n	n	n	n
CP n=174	145	9	3	12	1	0	1	3
SBC n= 23	21	1	0	0	0	1	0	0
Total n=197	166	10	3	12	1	1	1	3

(164/197 = 83.2%) were living in the primary marriage; 2 (1%) were remarried. Length of marriage varied considerably (0-32 years).

As in general, quite a few parents in the study were not married but lived together in a serious long-standing relationship (n=10; 5.1%); a cohabitation in consensual union.

Thus, a total of 89.3% of the children with CP or SBC were living in nuclear families - with a father as well as a mother figure (Table 27). This rate corresponds well with the average (89%) of MLL households (with children 0-17 years) (42). Of the children who had a single parent (10.7%), the father was missing four times as often as the mother.

Divorce rate of parents

The relative number of divorces in Sweden in each marriage cohorts by number of years since marriage, 1955-76 was for 5, 10 and 15 years 10.3%, 15.5% and 17.5%, respectively (78).

Biological parents of children with CP or SBC who married 5 years or more before the investigation (n=171), 10 years or more before the study (n=131) and 15 years or more before the study (n=66) had a divorce rate of 11.7%, 13.0% and 18.2%, respectively.

Of the 21 divorced parents the divorce occurred after 2-23 years of marriage, the median being 9 years.

Parents' social class

The distribution of the interviewed families according to social class did not differ from the distribution of all families with motor handicapped children in MLL or from Swedish families in general (Chapter III).

Nationality of parents

The nationality of biological parents of the children with CP or SBC is shown in Table 28. For comparison the average figures are given for the Swedish population as a whole (42).

Table 28. Nationality of biological mothers and fathers of children with CP or SBC in MLL compared to the average population in Sweden. Percentage

	NATIONALITY				Total
	Swedish	Other Scandi- navian	Other than Scandi- navian	Not known	
	%	%	%	%	%
Mothers (n=196) of children with CP or SBC	90.9	4.0	4.6	0.5	100
Fathers (n=192) of children with CP or SBC	87.8	5.1	4.6	2.5	100
Swedish population average (42)	94.9	3.1	2.0		100

Age of parents

The age of parents at the time of birth of children with motor handicaps is not different from that of the average parents in Sweden (Chapter III).

Level of education

The level of education for the care-giving parents is shown in Table 29, where it is compared to the average (women and men aged 25-59) in Sweden (42). The figures are similar.

Table 29. Educational level of parents of children with CP or SBC in MLL compared to the average (women and men aged 25-59 years) in Sweden. Percentage

		Elementary school; lower sec- ondary school %	Senior secondary school; post- secondary education %	Total %
<u>Mothers of children</u>				
with CP	n=170	88.8	11.2	100
with SBC	n= 23	95.7	4.3	100
Total	n=193	89.6	10.4	100
<u>Fathers of children</u>				
with CP	n=159	83.0	17.0	100
with SBC	n= 22	77.3	22.7	100
Total	n=181	82.3	17.7	100
<u>Average (women and men aged 25-59 years) for Sweden</u>				
women		89.6	10.4	100
men	(42)	79.9	20.1	100

Parents' working capacity - outside the home

Except for 10, all the fathers (171/181 = 94.5%) were working full-time. This is in Table 30 compared to the average for economically active men (20-66 years) in MLL (42).

Table 30. Fathers of children with CP or SBC working outside home compared to the average man (20-66 years) in MLL. Percentage

	Not work- ing %	<u>Working part- or full-time (h/week)</u>			Data not avail- able %
		1-19 h %	20-34 h %	<u>≥ 35 h</u> %	
Fathers of children with CP or SBC n=181	4.4	0.5	0.5	94.6	
Average men (20-66 years) in MLL n= 147 611) (42)	12.4	1.7	3.4	81.0	1.5

Two fathers were working part-time, 1 of whom was also studying.

Out of the 8 non-wage-earning fathers, 2 were studying full-time, 2 were temporarily unemployed, 3 prematurely pensioned for health reasons and 1 was retired.

None of the fathers had given up work or reduced working hours because of the handicapped child.

Somewhat more of the mothers of children with CP or SBC were not working outside the home, compared to the average

woman (20-66 years) in MLL or the average woman with children (0-16 years) in Sweden (42). This is shown in Table 31. The most striking difference was that far more of the mothers in the study worked only part-time!

Table 31. Mothers of children with CP or SBC working outside home compared to the average woman (20-66 years) in MLL and the average woman (with children 0-16 years) in Sweden. Percentage

	Not work- ing %	Working part- or full-time (h/week)			Data not avail- able %
		1-19 h %	20-34 h %	<u>≥</u> 35 h %	
Mothers of children with with CP or SBC n=193	40.9	14.0	31.1	14.0	
Average women (20-66 years) in MLL n= 146 265 (42)	34.8	9.3	20.9	33.9	1.1
Average women (with children 0-16 years) in Sweden (42)	30.8	10.2	27.1	31.8	

Three of the non-wage-earning mothers were studying.

Almost half ($71/163 = 43.6\%$) of the mothers who were not working or studying full-time, ascribed this to the child's handicap. Significantly more ($p < 0.05$) mothers did work when their children with CP or SBC were mentally normal or dull ($94/144 = 65.2\%$) than if their children were also mentally retarded ($24/49 = 49.0\%$).

Organized leisure time of parents

Almost half of the parents of children with CP or SBC - the same proportion of mothers and fathers - did attend organized leisure time activities such as classes, sports, etc. (Table 32). Parents participated - mothers in the same proportion as fathers - as frequently as once a month or more often in organized leisure time activities (mothers 44.6%; fathers 44.7%).

Table 32. Intensity of organized leisure time activities for parents of children with CP or SBC in MLL.
Percentage

		INTENSITY				Total
		None	<once a month	<once a week - once a month	≥once a week	
		%	%	%	%	%
<u>Mothers</u> of children						
with CP or SBC	n=193	54.4	1.0	4.7	39.9	100
<u>Fathers</u> of children						
with CP or SBC	n=181	53.1	2.2	7.7	37.0	100

Organized leisure time activities were as common among working and studying mothers as among the other mothers in the study (45.8% vs. 45.3%).

Mothers without work, studies and organized leisure time

Forty-one mothers (of 37 children with CP and 4 with SBC) were without work outside the home, were not studying and did not have any organized leisure time activities. Two of these mothers had their children cared for in institutions. Three (of these 41) mothers did not have a husband or cohabitation partner.

Significantly more ($p < 0.02$) of the children of these mothers were in the preschool age ($\sim 4-6$ years of age), i.e. 48.8% (20/41) vs. 28.9% (44/152). Thus, there was a correlation between the child being of low (pre-school) age and the mother's lack of work, studies and organized leisure time activities. The children with CP or SBC of these mothers ($n=41$) were not more often severely mentally retarded, not significantly more often severely motor or severely totally handicapped than the others ($n=152$). There was also no difference concerning the frequency of epilepsy in children of these and of the other mothers of children with CP or SBC.

Institutional care - long term relief

Parents of 18 of the 197 children with CP or SBC had their children cared for in institutions all year round ($n=14$) or during school term ($n=4$). This means that 183 children were cared for in their homes permanently ($n=179$) or during holidays and vacations ($n=4$).

Of the children permanently cared for in institutions and born 1965-72 ($n=9$; including those not interviewed) all were severely mentally retarded.

Regular child care in day-time nurseries

Day-time nurseries offer special care and developmental training for children. Because of this and the parents' work outside the home and/or their relief, 34 of the investigated children had full day-care in nurseries (Fig. 10).

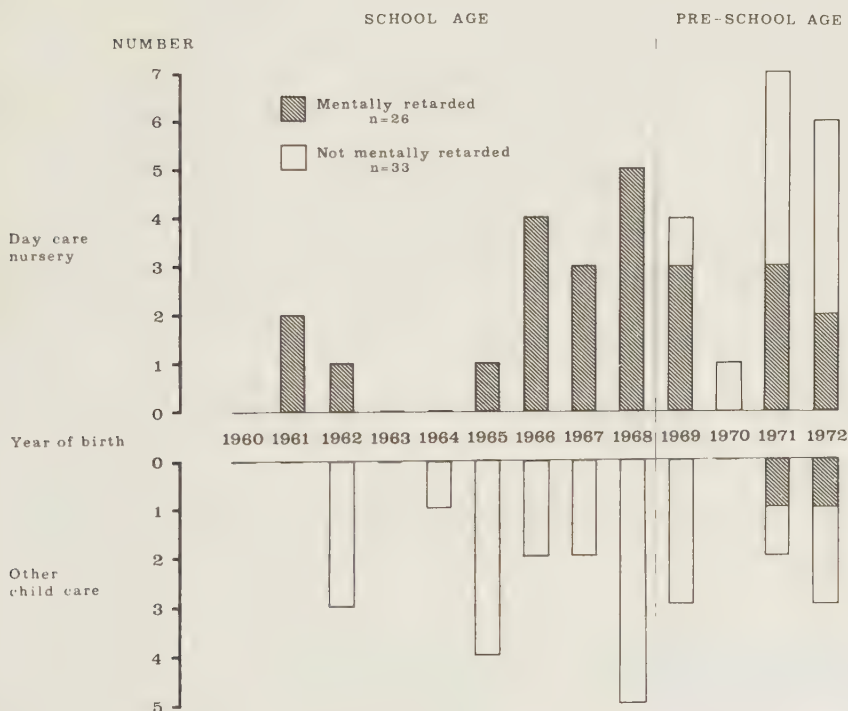


Fig. 10. Day-care nursery and other child care by year of birth of children with CP or SBC

Sixteen mentally retarded children of school age (~7-16; born 1960-68) were in special county nurseries, as were 5 of the 18 preschoolers, 12 were in regular municipal day nurseries while 1 attended both. Nearly all of these parents ($28/34 = 82.4\%$) were satisfied with the care and education at the day nurseries. Parents of 7 mentally retarded children were not satisfied and wanted more advanced education (6 children) and/or increased stay per day for their children.

Regular day-care by others than parents or nursery

Twenty-five of the children with CP or SBC received regular day-care by persons other than parents or nursery (Fig. 10) because of parents' work outside the home or for their relief. Seven children were cared for in their homes, 17 in the homes of private child-minders and 1 child in a municipal recreation centre.

Eleven of the children were cared for by relatives.

In 1976 in MLL only a total of 8 children in the age group 11-14 years had municipal family child-minders. Of these children 5 have motor handicaps and are included in this study.

Occasional relief - "baby-sitting"

Seventy-one per cent of parents of the 183 children with CP or SBC who lived at home permanently ($n=179$) or during

holidays and vacations (n=4), got occasional relief by "baby-sitters". Of the others, 13 (7.1%) wanted relief but were unable to obtain it. The remaining 40 families (21.9%) felt no need for relief as the majority of them (34/40) regarded their children as mature and old enough not to need "baby-sitters". However, 27.9% (17/61) of the families with children aged 12 years or more used "baby-sitters".

Most often the occasional relief was given by relatives (94/130 = 72.3%) or friends (6.9%). In 15.4% the "baby-sitter" was employed by the municipality. Seven families (5.4%) obtained their occasional relief mainly from an institution for severely mentally retarded.

Almost all of the parents who were using "baby-sitters" (98%) considered that the quality of help was satisfactory. However, a little more than one out of four of the parents were dissatisfied with the extent of the help (28.5%). Of all parents of children with CP or SBC mainly living at home, 27.3% (50/183) wanted (for 13 children) - or wanted more (for 37 children) - occasional help.

Many parents did not wish to be helped by just anyone but wanted special "baby-sitters" with experience of children with handicaps. If that kind of "baby-sitter" was available, 70 families felt they would gain from such a service. Some (10/70) would be content with this relief once or twice a year; the majority wanted more frequent relief by special "baby-sitters", preferably once a week.

DISCUSSION

Parents who had a child with a motor handicap did not differ from other parents according to age, level of education, social class or nationality. The slight excess of non-Swedish parents, especially fathers, in the study compared to the Swedish population in general is probably not specific for parents of children with CP or SBC, but reflects a higher proportion of immigrants in the MLL area.

More children in the study than the average were in foster homes. The severely handicapped foster children were in the care of grand-parents or other near relatives.

A handicap in a child always has an effect on the family unit. This effect can be devastatingly disruptive for some whereas for others it may be the cohesive force that holds the family together (71). Lagerheim found a higher rate of serious problems in Swedish families with motor handicapped children (72).

A high divorce rate in families with children with SBC has been reported by some (73, 74) while others report no raised divorce frequency (75, 76). McAndrew states that having a motor handicapped child often strengthens the parental relationship; and reports that in marriages where a breakdown had occurred, problems between the parents often preceeded the birth of the child (77).

This is called attention to also by Freeston (76). The rate of divorce among families in this study is not apparently different from the average family in Sweden (42). We believe that weak or bad relations between parents cannot withstand the great pressure a handicapped child puts on the family, while good relations between parents are sometimes strengthened and preserved by the parents' joint efforts to give optimal care to the handicapped child.

McAndrew found fathers to be little involved in the more specialized care of motor handicapped children (77). In the present study the fathers' ability to work was not affected by the handicapped child.

A somewhat larger number of mothers (of children with CP or SBC) did not work outside the home compared to the average woman (20-66 years of age) in MLL. It is likely that the difference would have been greater if figures for more comparable age groups, (e.g. 20-50 years - without pensioners - for the average woman in MLL) then had been available. The greater difference between the investigated mothers and the average woman with 0-16 year-old children in Sweden indicates this. Significantly fewer mothers (of children with CP or SBC) than the average worked full-time! This is related to most mothers feeling themselves strongly tied to the home and the care of the handicapped child.

Resources for care of mentally retarded children are much better than for motor handicapped children (with normal or dull intellectual capacity) in the MLL area. However, more mothers of this last group of children were working, than those of children who also had mental retardation. This fact is thought to depend on the mothers' finding themselves less restricted by the care of a motor than a multihandicapped child.

The figures for parents actively ($\geq$ once a month) attending organized leisure time activities correspond well to parents in Sweden with the youngest child 7-18 years of age (78). People working and/or studying (especially aged 15-44 years) are also more active in leisure time activities than those who do not work outside the home, especially women (78). However, the mothers of children with CP or SBC did attend to the same extent organized leisure time activities, regardless of whether or not they were studying or working outside the home.

When the mothers were not working outside the home, not studying and not active in organized leisure time activities, the main reason for this appears to be the low age of the handicapped child. This factor was more important than the severity of motor and total handicap or of the child having epilepsy.

Relatives - especially maternal grand-mothers - were often engaged as foster parents, for regular day-care and

also as "baby-sitters" for children with CP or SBC.

McAndrew found maternal grand-mothers to be the most frequent source of help outside the immediate family where the child's physical care was concerned (77). However, maternal grand-mothers often help their daughters with the children whether the children are healthy, sick or handicapped.

Even after 12 years of age - when non-handicapped children are expected, at least occasionally, to look after themselves - several of the children with CP or SBC have a need for "baby-sitters", sometimes this is supplied by relatives. However, there is a great need for "baby-sitters", with special knowledge concerning the care of handicapped children.

CHAPTER V

CHILDREN IN PRESCHOOLS -

DAY NURSERIES AND KINDERGARTENS

In Sweden 'preschools' is the collective term used for day nurseries and Kindergartens. In day nurseries children from 6 months to 6(-7) years of age are cared for all day; in Kindergartens groups of children 5-6(-7) years old attend for 3 hours a day for common activities. Both have an educational and social program.

Until recently the experience of nursery school or Kindergarten has been either totally denied to the severely handicapped or has taken place exclusively in segregated settings (78). However, today preschool opportunities are also available for motor handicapped children in special county preschools or in ordinary municipal ones.

In 1975 a preschool act was passed offering all children a place in the municipal part-time preschools (Kindergarten) during the year preceeding school start. It also enabled certain groups of younger children to be given priority for a place there or in the municipal day nurseries. The priority is meant to be for children who need extra training and stimulation in order to promote the best possible development, e.g. immigrant children, children with social problems and children with different

kinds of handicaps. This act has brought an increased amount of handicapped children into the ordinary preschools.

Even if the policy is to integrate children with handicaps into ordinary municipal preschools, there is still a need for special preschools. This is true e.g. for younger motor handicapped children in need of intensive physiotherapy, speech therapy, etc. In the MLL area the county council runs two special Kindergartens on a part-time basis for motor handicapped children.

The County Council Board for Provisions and Services to the Mentally Retarded is, among other things, responsible for education and training of mentally retarded children. Those who are of preschool age can receive individual training either integrated into municipal preschools or in the child's home. The board also runs nursing homes and special day-care centres with activities directed towards the needs of children with severe mental retardation. These centres are also attended by some severely mentally retarded children of school age.

Preschool activities

Sixty-four of the investigated children (n=197) with CP or SBC were of preschool age (born 1969-72). A total of 89.1% of these children were participating in different preschool activities (Table 33). Two fifth (40.6%) attended ordinary day nurseries or Kindergartens. Five of

these children and another 16 (total 21/64 = 32.8%) attended special Kindergartens for motor handicapped children. Twelve children were cared for in special preschools for mentally retarded, 1 of them was also in an ordinary day nursery. Five children attended other preschool activities, e.g. arranged privately or by the church.

Table 33. Types of preschool attended by children with CP or SBC in MLL

Total n of pre- school child- ren with CP or SBC n	ORDINARY MUNICIPAL <u>PRESCHOOL</u>		SPECIAL COUNTY PRESCHOOL for			Other n	None n
	Kinder- garten n	Day nursery n	<u>Motor handi- capped</u> Kinder- garten n	<u>Mentally retarded</u>			
				Day- care centre n	Nursing home n		
64	13 ^a	13 ^{a, b}	21 ^a	7 ^b	5	5 ^b	7

^aFive of the 21 children attending special Kindergartens for motor handicapped were also cared for in ordinary day nurseries (3 children) and Kindergartens (2 children)

^bOne child in a day-care centre for mentally retarded and 1 with "other" preschool activity were also cared for in ordinary day nurseries (2 children)

Seven children (10.9%) did not attend any preschool. Two of them were staying with family child-minders, 1 was expecting to be allocated a place in a day nursery, 1 was judged not to qualify for priority for preschool attend-

ance and 3 (all $3\frac{1}{2}$ years of age) were considered by parents to be "too young".

Four of the children of school age (born 1968) had a delayed school start and were still engaged in preschool activities. Three were severely mentally retarded and attended day-care centres for mentally retarded. One mildly mentally retarded child attended a special Kindergarten for motor handicapped.

Kindergartens

In Sweden only "older" preschool children (for the year preceeding school start; ~6 years of age) were (1976) guaranteed a place in ordinary Kindergartens. Twelve ($12/21 = 57.1\%$) of the older preschool children (born 1969) with CP or SBC attended ordinary Kindergartens; and 4 attended special Kindergartens for motor handicapped children. Thus, a total of 76.2% of the children with CP or SBC of this older age group were engaged in Kindergarten activities; compared to 83.6% of all children of that age in MLL (42).

Day nurseries

Thirteen (20.3%) of the 64 preschoolchildren studied were cared for and educated in ordinary day nurseries.

Special day-care centres and nursing homes for mentally retarded

Seven children were cared for and educated at special day-care centres for mentally retarded (1 of whom was also cared for in a municipal day nursery). Five children were cared for in nursing homes for severely mentally retarded.

Preschoolchildren - integration

Ten of the mentally normal (dull included) children studied were individually integrated in ordinary day nurseries, 13 in ordinary Kindergartens. Three of the mentally retarded (roughly $IQ < 70$) children were individually integrated in day nurseries (2 full-time, 1 part-time and for the rest of the day in a day-care centre for mentally retarded). Another 3 were integrated in a special Kindergarten for motor handicapped children; none of the mentally retarded preschoolchildren were integrated in ordinary Kindergartens.

Assistance in preschools

In special preschools for motor handicapped and in day-care centres or nursing homes for mentally retarded children the staff is designed to give every child the assistance he/she needs. In ordinary preschools the size of the staff is inadequate to cater for the needs of handicapped children. Therefore, when children with motor

handicaps are integrated in these preschools they are usually given a personal assistant.

According to staff, parents and examiners, 9 of the children with CP or SBC in ordinary day nurseries and Kindergartens, had a need for personal assistance. Of them 8 had a personal assistant, while only 1 child lacked one.

Adaptation of preschool buildings

In regard to accessibility (ground level or ramps) as well as enough spacious toilets-nursing rooms, the preschool buildings were suitable for all the 24 children with CP and 1 of the 2 children with SBC attending ordinary Kindergartens. Only 1 child with SBC attended an insufficiently adapted preschool building, e.g. without ramps.

Transport to the preschools

Children cared for in institutions usually had their preschool activities in the place where they lived.

Fifty-one of the preschool children with CP or SBC had a distance to travel to their preschool. One fourth (25.5%) walked or cycled, 17.6% were transported in family cars, 23.6% by special buses and 33.3% by taxi.

During the transportation 39.2% were accompanied by parents, 21.6% by personal assistant, whilst 39.2% were unaccompanied - most often children going by special bus or taxi.

DISCUSSION

By their activities the preschools should provide favourable conditions for intellectual, social and emotional development of all children. The preschools are supplements to the home and activities are pursued in close co-operation with the parents. Such a program is even more important for handicapped children, who by law are given priority.

As a supplement to these ordinary preschools there are - in MLL as in other parts of Sweden - some special preschools for motor handicapped children. These preschools offer regular preschool activities which are supplemented by contact with the habilitation team, with their medical, psychological and social functions. As far as possible children with motor handicaps usually leave these special preschools for integration in ordinary preschools for at least their last preschool year, before starting in comprehensive school at 7 years of age.

In ordinary day nurseries they have more staff, children of various ages and thus preschool education at more varied levels than in ordinary Kindergartens. Therefore, it seems logical that integration of mentally retarded motor handicapped children had begun in day nurseries but had not started in ordinary Kindergartens at that time (1976).

Far more of the preschoolers were 1976 (compared to 1966) occupied in preschool activities (89% vs. 50%) (25).

The present Swedish policy is to achieve a primary integration of motor handicapped children in ordinary preschools, if necessary with personal assistants, and with physiotherapists and other members of the habilitation team visiting the preschools for treatment of the child and for instructions to the personnel. Resources for this highly desirable care are very limited in some parts of Sweden, e.g. in MLL.

The need for personal assistance was well catered for and transportation for the children with CP or SBC, in connection with preschool visits, was satisfactorily arranged.

Preschools have, for a long time, been built in a manner which make them suitable and safe for children. Therefore, it is not surprising that the preschool buildings were usually found to be satisfactory also for motor handicapped children.

The children with CP or SBC participated in a most satisfactory rate in preschool activities, more frequently than the average child in MLL. On the other hand, the types of preschool activities varied more and were also geographically more widely separated for these children, which meant more travelling. Some children went to both special

and ordinary preschools. Attending double preschools can be tiresome for children. They meet with different children, different staff and usually they have to travel a lot. On the other hand, they have the advantages of extra therapeutic resources in the special preschool as well as getting to know their local non-handicapped peers in the ordinary preschool. The best way, for the majority, would be primary integration in ordinary preschools, supplemented, when needed, with personal assistance and with special care and treatment given by mobile habilitation teams visiting them.

CHAPTER VI

CHILDREN IN SCHOOL

Swedish children have a basic education of 9 years comprehensive compulsory school starting the year the child is 7 years old. A voluntary senior secondary education for 2-4 years is then chosen by close to 80% (80).

Compulsory education has gradually been introduced also for children with severe handicaps. Already in the late 19th century education was started in state schools for children with visual or hearing impairment. Children with mild mental retardation have had the right to education since 1944. These rights were given to children with all degrees of mental retardation in 1968 (Act for Service and Provisions for Mentally Retarded Persons) (53). These children and young people have compulsory education in special schools ("särskola") up to the age of 20 or even 23. The education is based on two different levels. Children who are mildly mentally retarded (IQ roughly 50-69) are educated in special classes ("särklass") in ordinary comprehensive schools or in special elementary schools. This education comprises many of the same subjects found in ordinary classes, but is given to small groups of children. Severely mentally retarded (IQ roughly <50) children get tuition in groups ("träningsklass") or individually. The special tuition stresses training in

activities connected with daily living (ADL) and is offered to the child at special institutions, day-care centres or at home.

Some special schools still exist for children with mental retardation, deafness or blindness. If the main problem of a motor handicapped child is within these areas, one of those special schools - or special schools for children with combined handicaps - might offer the best educational possibilities.

For motor handicapped children school education was not obligatory until 1962. At that time there were special residential schools for the motor handicapped. Severely motor handicapped children with need of very special education, of care and training can still be referred to special classes, sometimes located in the few special schools for motor handicapped. However, most children with motor handicaps nowadays attend ordinary comprehensive schools, the majority being individually integrated in ordinary classes with or without personal assistance. For those who need supplementary special education; this is offered on an individual basis in special study groups of regular classes, or in special classes in ordinary comprehensive schools.

In Sweden there are 7 consultants (teachers) working as advisers in comprehensive schools where motor handicapped children are individually integrated. These consultants

also work with the integration procedure for the motor handicapped child and they are active in co-ordinating work between family, school and habilitation team.

School education of children with CP or SBC

A total of 140 children with CP or SBC in MLL were of compulsory school age (7-16 years; born 1960-68). Of them 118 were living at home travelling daily to school, 18 were educated in institutions where they were resident (4 in institutions for motor handicapped, 1 in an institution for hearing disabled and 13 in institutions for severely mentally retarded). Starting school was delayed for the remaining 4 (mentally retarded) children.

Parents of 133 of the children with CP or SBC participated in this interview part of the investigation. In Table 34 the type of education is given for the 133 (and

Table 34. Type of education for schoolchildren with CP or SBC

		TYPE OF EDUCATION					
		At comprehensive school level		Special education for mentally retarded		Delay of school start, preschool activities	
		n	%	n	%	n	%
CP or SBC							
n=133		99	74.4	30	22.6	4	3.0
(n=140		102	72.8	34	24.3	4	2.9)
Sweden average children 7-16 y			99.3		0.7		

140) children. The 4 mentally retarded children with delayed school start were cared for in special preschools for motor handicapped children (three) and in a day-care centre for mentally retarded (one). This leaves us with a group of 129 children receiving school education, 99 at comprehensive school level and 30 having special education for mentally retarded.

Distribution of children educated at comprehensive school level

Three out of four (99 children) were educated at comprehensive school level. Sixty-nine of them were individually integrated into ordinary classes (Table 35).

Sixteen received their education in special classes for motor handicapped and 12 in classes located in ordinary comprehensive schools, 4 in residential schools for motor handicapped. One child was educated in a residential school for hearing disabled.

Thirteen children at comprehensive school level were educated in special remedial classes located in ordinary comprehensive schools. These classes used to have few pupils per class and were often located in only one of the schools in the municipality.

The rate of children with CP and SBC was the same in ordinary classes.

Table 35. Distribution of schoolchildren with CP or SBC at comprehensive school level and special education for mentally retarded. Percentage

	AT COMPREHENSIVE SCHOOL LEVEL (76.8%)				SPECIAL EDUCATION FOR MENTALLY RETARDED (23.2%)				Total
	ORDINARY		SPECIAL		SPECIAL		SPECIAL		
	class	%	remedial class (learning difficulties)	class for motor handicapped	class for hearing disabled	class	training, in groups	individual training, (in institutions, day-care centres or at home)	
CP n=116	53.4		10.4	11.2	0.9	4.3	11.2	8.6	100
SBC n= 13	53.8		7.7	23.1	0	7.7	7.7	0	100
Total n=129	53.5		10.1	12.4	0.8	4.6	10.9	7.7	100

The system of special remedial classes has through the years been replaced more and more by special teachers giving supplementary education to pupils in need of this - co-ordinated remedial instruction. It is available in both theoretical and practical subjects. Co-ordinated remedial instruction is available in all comprehensive schools and is believed to be of great importance for individually integrated motor handicapped children. Of the pupils individually integrated in ordinary classes ($n=69$) almost half ($CP\ 28/62 = 45\%$; $SBC\ 4/7 = 57\%$) received this kind of instruction. All ($4/4$) of the children with SBC who had co-ordinated remedial instruction had it in only one subject, whereas half ($14/28$) of the children with CP had it in two or more subjects.

Thus, about 65% of the children at comprehensive school level needed - and mostly received - extra pedagogic support in one way or another (Table 36).

Type of education for mentally retarded

Six (of the 30) children with mental retardation were educated at the level of a special class for mentally retarded and 14 received special training in groups (Table 35). Almost half ($9/20$) of these children were educated in small groups in ordinary comprehensive schools. Another 10 of the mentally retarded schoolchildren had special individual training at institutions for severely

Table 36. Extra pedagogic support for children with CP or SBC at comprehensive school level

TYPE OF CLASS OR SUPPORT	n	%
Special class for motor handicapped	16	16.2
" " " hearing disabled	1	1.0
" remedial class	13	13.1
Co-ordinated remedial instruction in		
theoretical subjects	29	29.3
practical " "	3 <u>62</u>	3.0 <u>62.6</u>
No co-ordinated remedial instruction		
but <u>need</u> of	2	2.0
No apparent need of extra		
pedagogic support	35	35.4
Total	99	100

mentally retarded or in day-care centres. Thus, all mentally retarded schoolchildren had some type of special education or training.

Parents' opinion on school and education

The vast majority (90%) of the parents were satisfied with school, class and type of education for their children. Some parents wanted education given to their child in a school closer to home, thereby avoiding tiring daily journeys. Others wanted education in smaller - sometimes also more homogeneous - groups. Parents of 4 children in special remedial classes wished to have their child

integrated into an ordinary class. Most parents (23/32 = 71.9%) were satisfied with the co-ordinated remedial instruction, 8 children were by their parents thought to have too little and 1 child too much. The parents of another 2 children wanted this extra pedagogic support which their children had not yet received.

Personal assistance in school

Many children with motor handicaps need personal assistance in school. This need is well catered for in special classes and schools for motor handicapped children. Also in ordinary comprehensive schools the child can have a personal assistant when needed.

A block grant is paid out to all municipalities from the National Board of Education as a help to cover costs for personal assistance. Any additional costs are paid by the municipality. The grant is based on the number of pupils in the area.

As illustrated in Table 37 the vast majority of children with SBC and a minority of children with CP needed personal assistance in school. Nearly all of those needing personal assistance had received it.

Sixteen of the children with CP or SBC educated at comprehensive school level (n=99) only had assistance on arrival, departure or at breaks. Another 12 also had a personal assistant during lessons.

Table 37. Personal assistance of children with CP or SBC in school (within brackets in ordinary, special remedial and hearing classes - not special classes or schools for motor handicapped children)

	PERSONAL ASSISTANCE			Total
	Yes - adequate	No - but need	No - without	
	%	of %	need of %	%
CP n=116 (75)	16.4 (17.3)	3.4 (4.0)	80.2 (78.7)	100
SBC n= 13 (8)	69.2 (87.5)		30.8 (12.5)	100
Total n=129 (83)	21.7 (24.1)	3.1 (3.6)	75.2 (72.3)	100

Adaptation of school buildings

When adaptation of school buildings prove to be necessary the municipality can apply for a special state grant which only covers a fraction of the total cost. The rest is paid by the municipality.

Most (93%) of the school buildings, where children with CP or SBC attended comprehensive school, were judged by parents and the social worker to be sufficiently adapted (Table 38). The school buildings were often more suitable for children with CP than children with SBC (96.6% vs. 61.5%; $p < 0.001$).

Table 38. Adaptation of school buildings for children with CP or SBC in school (within brackets children in ordinary, special remedial and hearing classes - not special classes or schools for motor handicapped children)

	ADAPTED SCHOOLS				Total
	Sufficient %		Insufficient %		%
CP n=116 (75)	96.6	(96.0)	3.4	(4.0)	100
SBC n= 13 (8)	61.5	(50.0)	38.5	(50.0)	100
Total n=129 (83)	93.0	(91.6)	7.0	(8.4)	100

Daily travel to school

A total of 116 of the schoolchildren with CP or SBC had a varying distance to go to school. Three out of four walked, cycled or used the public transportation system. The others (n=29) were transported by taxi or special buses.

Most children (90%) went to school unaccompanied by parents or assistants. Half of the remaining 10% were accompanied by their parents.

DISCUSSION

All children in Sweden are guaranteed education.

For mentally retarded - also motor handicapped - education is organized and supervised by the County Council Board for Provisions and Services to the Mentally Retarded. Tuition is given in special schools, special classes - often integrated in ordinary comprehensive schools - in day-care centres or other institutions or individually at home.

Motor handicapped children at compulsory school level - especially when they have severe associated handicaps - sometimes go to one of the few residential schools for motor handicapped children. This school has special facilities and staff with considerable skills and interest in the problems of the motor handicapped child. However, there are obvious disadvantages in separating young children from their families, relatives and friends in the home community. There is a risk of isolation and institutionalisation that makes the handicapped child an adult ill-prepared for the outside world.

In Sweden - as in many other countries - there is a trend to minimize the number of special, residential schools, and instead to have motor handicapped children in special classes or individually integrated in ordinary classes in comprehensive schools.

In the present study starting school was delayed for just 4 of the schoolchildren; all of them were occupied in pre-school activities. In 1966 starting school was delayed for 8.8% (17/194) of the motor handicapped schoolchildren; almost half of them lacked also preschool activities.

Most schools in Sweden are built or adapted to be suitable also for motor handicapped children. In the present investigation this was true for the vast majority of children with CP, significantly less often for children with SBC. Their greater demand on school buildings for ease of access, ramps, hand rails and also spacious and specially equipped toilets-nursing rooms, was not enough taken into consideration. However, sometimes factors other than a well-adapted building are important: e.g. the personal relationship to peers - from preschool and from the neighbourhood - can make parents and child prefer an old and less comfortable school nearer home.

The transportation to and from school was usually well organized and raised no serious obstacles. Nearly all children needing personal assistance had received it.

Mitchell states that talking to young handicapped adults makes it clear that there is nothing they desire more than to be accepted on equal terms with their peers and that they want no privilege or special attention beyond what is essential for their disability (82). Even severely motor handicapped children can manage well in special

classes for motor handicapped children in ordinary schools. Some motor handicapped children have been able to take advantage of the education in the small groups in special remedial classes. However, these classes are being withdrawn. This means that some motor handicapped children with borderline intellectual functions will be referred to special classes for mentally retarded. Others will be individually integrated into ordinary classes, which is what most parents want. However, some will have disadvantages in going into bigger classes and will also risk problems in their contact with peers (83). There is an apparent need for more special remedial instruction when motor handicapped children are individually integrated into ordinary classes. Integration into ordinary class, with enough special remedial instruction, is by most teachers and parents judged to be the most stimulating educational setting (83). Already there is a shortage of special remedial instruction. In times of economic restraint these resource intensive activities are likely to be cut even though an increase in such efforts is desirable. However, this matter must be solved to achieve an optimal, individual integration of motor handicapped children in ordinary classes; the form of education that also is the goal of organizations for the handicapped, the National Board of Education and the National Board of Health and Welfare.

CHAPTER VII

LEISURE TIME ACTIVITIES

The social life of a motor handicapped child is strongly dependent on e.g. family relations, as well as preschool and school conditions. However, for a satisfactory quality of life, leisure time activities and contact with peers are of vital importance.

Activities together with family

At least sometime during the year most of the children with CP or SBC ($188/197 = 94.4\%$) did participate in social activities with their families outside the home. These activities comprised of visits to relatives, shopping trips, going to movies, etc. Most of the children (70%) participated in family activities of this kind as often as once a week or more. The 9 children who never participated were all severely multihandicapped; 8 lived in institutions for severely mentally retarded.

Out of the 179 children who lived permanently at home all participated in family activities, 76% once a week or more.

Organized leisure time activities

A little more than half (55.6%) of the 133 children of school age with CP or SBC (with no difference between

the two diagnostic groups) were occupied in organized leisure time activities such as sports, scouting, music, hobbies, etc. (Table 39). Half of the children participating in sports were active in swimming, two out of three of them in the form of Halliwick swimming. One third of the schoolchildren active in sports and/or activities like scouting, music, hobbies (24/74) had two or more different leisure time activities per week.

Table 39. Organized leisure time activities for school-children (born 1960-68) with CP or SBC in MLL.
Percentage

	ORGANIZED LEISURE TIME ACTIVITIES			NO ORGANIZED	Total
	Sports	Others	Sports	LEISURE TIME	
	(only)	(only)	and/or	ACTIVITY	
	%	%	%	%	%
All school-children ≥ 7 years n=133	36.8	30.1	55.6	44.4	100
Schoolchildren ≥ 12 years, living at home n= 55	41.8	29.1	63.6	36.4	100

Fifty-five children were aged 12 years or more and living at home. Altogether 63.6% of them (35/55) attended organized leisure time activities once every second week or more often. The same applied to 66.0% of the 47 intellectually normal (roughly IQ >70), whereas 4 of the 8 mentally re-

tarded children (of this age group) had no organized leisure time activity.

Free leisure time activities - older schoolchildren

Of the 55 children aged 12 years or more living at home, 27 (49.1%) participated in free leisure time activities such as going to movies, disco, sports events, etc. with friends or on their own (Table 40). None of these 27 children were mentally retarded. Thus, 57.4% (27/47) of the mentally normal children (12 years or more, living at home) had free leisure time activities. Nineteen (40.4%) took part in activities like this every third month or more often - 8 of them as often as once every 1-2 weeks. In the latter (most active) group none had a severe motor

Table 40. Free leisure time activities for children with CP or SBC living at home, ≥ 12 years of age, in MLL. Percentage

Intellectual capacity	FREQUENCY OF ACTIVITIES				Total
	$\geq$ once a week	< once a week - once every 3 months	< once every 3 months - once a year	< once a year	
	%	%	%	%	%
IQ ≥ 70 n=47	17.0	23.4	17.0	42.6	100
IQ ≤ 70 n= 8	0	0	0	100	100
Total n=55	14.5	20.0	14.6	50.9	100

handicap. One third (10/28) of the children living at home, 12 years of age or more, who had no free leisure time activities were severely totally handicapped.

Parents considered the severity of the handicap or transport problems the reasons for 12 children not being able to participate in free leisure time activities. When transport reasons were said to be the cause, 1 child had a severe and 2 a slight total handicap; when handicap reasons were stated, all children had a severe (6 children) or moderate (3 children) total handicap. Parents of 6 children regarded their child as being "too young", others (parents of 10 children) said the child "did not want" to participate in free leisure time activities. Only 1 of these children had a severe, 4 a moderate and the vast majority (11/16) just a slight total handicap.

Contacts with peers

Among the children with CP or SBC (n=197) 86.3% were by parents said to have contact with other children of the same age, at least once a month; 67.5% once a week or more often (Table 41). Two out of five had roughly one daily contact; only 4.6% never met children of their own age.

More than half (55.8%) of our children visited peers on their own once a month or more often; two thirds were themselves visited as frequently by their peers -

Table 41. Contacts with peers - visiting or visited by - among preschool- and schoolchildren with CP or SBC in MLL. Percentage

		FREQUENCY OF CONTACT					Total
		> once a week	(w/daily)	< once a week - once a month	< once a month (never)		
		%	%	%	%	%	%
Preschool- children with CP or SBC	n= 64	75.0	(43.7)	15.6	9.4	(4.7)	100
Schoolchildren with CP or SBC	n=133	63.9	(39.8)	20.3	15.8	(4.5)	100
Total	n=197	67.5	(41.1)	18.8	13.7	(4.6)	100

unsupported by parents (Table 42). More than one third of the children had peer contact on their own roughly every day; only 3 children depending on parents' support had such frequent contact.

Fourteen per cent (17/120) of the schoolchildren living at home; 3% (3/96) of the children living at home who were 12 years of age or more, with normal intellectual ability, were never on their own visiting, or visited by, peers.

There was no statistically significant difference in frequency of peer contact, once a week or more often, between preschool (75.0%; n=64) and school age children (63.9%; n=133) nor was there a significant difference between

Table 42. Children with CP or SBC visiting, or visited by, peers - with or without parental support. Percentage

	FREQUENCY OF CONTACT					Total
	>once a week (daily)	<once a week - once a month	<once a month (never)			
	%	%	%	%	%	%
Visited peers on their own n=197	45.2	(34.0)	10.6	44.2	(37.0)	100
Visited peers together with parents n=197	26.9	(1.5)	38.6	34.5	(10.2)	100
Were visited by peers on their own n=197	53.8	(35.5)	13.2	33.0	(23.9)	100
Were visited by peers together with parents n=197	24.9	(1.0)	42.1	33.0	(9.6)	100

children with CP compared to children with SBC (67.8% vs. 65.2%) in regard to the frequent (once a week or more often) peer contact.

Municipal transport service

Each municipality has its own rules for transport service for handicapped people; regarding eligibility, frequency of travel, distance, etc.

Families of 29 (14.7%) children with CP or SBC - mostly of school age (25 children) - used this municipal transport service, mainly for planned, recurrent events, such as leisure time activities.

Another 46 children (23.4%) had handicaps that (according to social worker) would have qualified for this transport service but their parents had not applied.

Applications for transport service had been turned down for 2 families. Four others were dissatisfied with the limited transport service they were receiving.

DISCUSSION

Generally children get a lot of pleasure, social experience and developmental stimulation by going places with their family, participating in leisure time activities and by contact with other children. This, of course is also applicable to children with handicaps. Therefore, it is encouraging that the vast majority of our children

did have social activities, most of them every week.

McAndrew found just over one third of her motor handicapped children, who were 8 years of age or older, involved in organized group activities, e.g. church groups, cubs, brownies. A quarter of these children belonged to the groups catering for physically handicapped children only (77).

In a village near Lund 70% of the schoolchildren aged 11-15 years had organized leisure time activities; in another village 85% of the 10-year-old children participated (84).

In this study 55.6% of the children 7 years of age or more and 63.6% of the children 12 years of age or older and living at home participated in organized leisure time activities. Even though the figures are lower than those reported by Kornfält (84), they were not alarmingly so.

Most of the children in the present study participated in swimming, ordinary or in the Halliwick form. This is not surprising since water activities give apparant physical as well as psychological advantages to children with motor disabilities.

Because of the severity of the handicap some children were unable to participate in free leisure time activities such as going to movies, disco, sports events, etc. with friends or on their own. However, it is likely that most of the 11 children - with a slight total handicap and

12 years of age or older, who were said by parents to be "too young" or "not wanting to" participate in these activities - were overprotected and their capability underestimated by the parents.

Meeting other children of their own age is very important for all children. Of schoolchildren with SBC in the present study about half (8/14) were visited daily or almost daily by peers. In another study from the whole of southern Sweden, the corresponding frequency was similar (45.8%) (21). In the present study roughly two thirds of the children with CP or SBC were visiting or being visited by peers once a week or more.

McAndrew found half of her motor handicapped children - but predominantly children with CP - having no-one to play with when at home, possibly seriously affecting their ability to learn about social interaction with other children (77).

Dorner reported half of her adolescents with SBC to be severely socially isolated, particularly those attending special schools (85). They had not been visited at home, nor had they themselves visited, or gone out with, any friend of their own age, handicapped or non-handicapped, for at least one month prior to the time of the interview. Her findings speak in favour of integration into ordinary schools.

In a Swedish study 12% of integrated motor handicapped

schoolchildren were without contact with peers (83).

It is important with extensive encouragement and facilitation of handicapped children's peer contact in and outside school (21). When reaching adolescence the risk of social isolation increases especially when no earlier, firm peer contact has been established.

Peer contact is often thought to be more intensive between schoolchildren than it was during their preschool days. However, the frequency of seeing other children was in this study the same in the preschool as in the school age. When depending on help from another person it may be more natural for a preschooler to meet peers together with e.g. parents, than it is when the child is more grown up. Then (schoolchildren-adolescents) the motor handicapped child is often also more dependent on aids and handicap adjustments.

The frequency in which children with CP or SBC in this study met other children of their own age seems to be satisfactory. Nevertheless, the findings that 14% of all children of school age, 3% of the schoolchildren living at home, 12 years of age or older, with normal intellectual ability, never met peers on their own is unsatisfactory. Comparable figures have not been found in the literature. The quality of contact has not been estimated or analysed in the present survey. Quantitative facts can easily be gathered, while quality of social contacts, e.g.

the depth and satisfaction, is difficult to evaluate and therefore is mostly missing.

Several parents did not use the community transport service, also parents of children who were judged by social worker to have qualified for this service. The reason for this was mostly the parents' preference for going places in their own car, this being the quickest and simplest form of transportation for the family. Moreover, municipal transport service has to be ordered ahead and thus stops impromptu trips.

CHAPTER VIII

HOUSING

A relatively large proportion of people in Sweden live in small, mostly one-family houses (43.5%), especially in sparsely populated areas (93.3% vs. 34.1% in localities). The average number of rooms per dwelling, including kitchen, is 3.9. The standard of housing is generally very good with 87.1% of households having all modern conveniences (42).

Geographic distribution in MLL

Families with children with CP or SBC (n=197) were distributed in the communities in the same way as the general population in MLL (42). Thus, motor handicapped children were concentrated neither to the densely nor to the sparsely populated areas.

Living in small houses or apartments

Two thirds of the families with children with CP or SBC lived in small houses (Table 43); this is close to the average child family (children 0-17 years) in MLL (42).

Quality of dwelling

Officially, quality of dwelling is usually divided into seven groups. Groups 1-2 have all modern conveniences, group 3 has the same but no bath or shower, in group 4-7 there

Table 43. Distribution of families with children with CP or SBC and the average child family in MLL according to type of housing. Percentage

	Small houses %	Apartments %	Total %
CP or SBC n=197	69.0	31.0	100
Average child (0-17 years) family in MLL n= 71 317 (42)	63.8	36.2	100

is partial or total lack of modern conveniences; only group 7 has no piped water and/or drain.

The vast majority (97.5%) of the families with children with CP or SBC as well as the average child (0-17 years) family (94.6%) in MLL (42) belonged to the group with the highest quality of dwelling (Table 44).

Table 44. Quality of dwelling for families with children with CP or SBC compared to the average child family in MLL. Percentage

	QUALITY GROUP OF DWELLING				Total
	1-2 %	3 %	4-7 %	Not known %	%
CP or SBC n=197	97.5	1.5	1.0		100
Average child (0-17 years) family in MLL n= 71 317 (42)	94.6	1.7	3.5	0.2	100

Ground level access

One fourth of the slightly-moderately motor handicapped children (n=135) and 17.7% of the severely motor handicapped children (n=62), lived without ground level access. Nine (14.5%) of the latter group had their apartments upstairs with no elevator. Five of these children were cared for in institutions most of the time.

Number of rooms; over-crowding

In Sweden over-crowding is considered present when the number of occupants exceeds 2 per room, exclusive of both kitchen and one of the rooms (42). Using this definition only 12 (6.4%) of our families (with children living at home or visiting regularly; n=187) were over-crowded compared to 9.7% among families with children 0-17 years in MLL (42).

The number of rooms, including kitchen, for families with children with CP or SBC was 5.7 per dwelling.

Adaptation of dwelling - allowance for housing adjustment

Motor handicapped children need extra space and often housing adaptations to get the best use of the dwelling.

In order to give handicapped persons of all ages a possibility of housing adaptation, there is a special allowance for housing adjustment with an upper limit (1976) of

15 000 SKr (roughly \$ 3 400 or £ 1 800). The allowance is paid out for e.g. removing of doorsteps, widening of door openings, rebuilding of bathroom, etc.

One fifth (20.3%; $n=187$) of our families had their flats and private homes specially adjusted. However, about one out of three (13/38) needed (judged by parents and social worker) further adjustment (Table 45).

In most families ($149/187 = 79.7\%$) no adjustment was made, but 19.5% ($29/149$) of them had an apparent need for it. Families with children with SBC needed, or needed more, adaptation more often than those with CP ($9/23$ vs. $33/164$; $p<0.05$). Of all families who needed ($n=29$), or needed more ($n=13$), adjustment, more than half ($25/42$) were actively planning for it, while 6 had not taken any measures in this respect. It was not possible to adapt 5 of the dwellings. Two families had been denied the allowance.

Housing adjustments had been done at the same rate whether the family had received (10.7%) the allowance for handicap adjustment or not (9.6%) (Table 45). When the adjustment was made with the allowance there was less often need of further adjustment, compared to when the adjustment was made without the allowance (20.0% vs. 50.0%).

Until the interview, three families were unaware of the need for adjustment and one family did not know about the allowance.

Table 45. Housing adjustment - with or without allowance - for families with children
with CP or SBC in MLL

Housing adjustment	Diag- nosis	HOUSING ADJUSTMENT						Total
		Made - without further need	Not made - not needed	Made - with further need	Not made - but needed	n	%	
Made - with allowance	CP SBC	11 5		3 1				
		16		4		20	10.7	
Made - without allowance	CP SBC	9 0		6 3				
		9		9		18	9.6	
Not made	CP SBC		111 9		24 5			
			120		29	149	79.7	
Total		25	120	13	29	187	100	143

Municipal handicap rent allowance

Six of the families with children with CP or SBC had a municipal handicap rent allowance (see Chapter X).

Room at child's disposal. Bedroom sharers

The children with CP or SBC who permanently or in periods lived in their family homes (n=187) had in 60% of cases a room at their own disposal.

The children used in 18.2% of cases the same bedroom as their parents, with no significant difference between schoolchildren and preschoolers (20/126 vs. 14/61). Regardless of age, 34.6% of the severely motor handicapped children (n=52) and only 11.9% of the others (n=135) shared bedrooms with their parents ($p < 0.001$). One fourth of the children with or without epilepsy (also irrespective of age) shared bedrooms with their parents. The lowest ratio (9.6%) of bedrooms sharers were the schoolchildren who had neither a severe motor handicap nor epilepsy (n=83); the severely motor handicapped schoolchildren (n=27) had the highest rate (37.0%).

DISCUSSION

The care of a child - particularly a handicapped one - is made easier by having good family living conditions. Nearness of habilitation resources is important for families with motor handicapped children. In MLL there is a concentration of habilitation resources to the two largest

cities, and the only county district service which exists is a very limited amount of physiotherapy. In spite of this, there is no concentration of families with motor handicapped children in the two larger cities. The fact that so many families stay in sparsely populated areas may be related to psychological (human relations) advantages for them compared to living in cities. Also, small houses with ground level access are easier to find outside cities. Besides, from all parts of MLL, the paediatric clinics with habilitation facilities can be reached by car within an hour.

A quarter of the parents in McAndrew's study reported that their current accommodation was not entirely suitable for the child (77). In the present study the housing standard was very high for families with children with CP or SBC and higher than that of families without handicapped children in MLL (42) - with regard to living in small houses, having enough rooms per person and having all modern conveniences. In all these respects, the standard was higher in the 1976 than in the 1966 study, e.g. lack of modern conveniences only, 2.5% vs. 9% (10). This is to some extent due to special arrangements for families with motor handicapped children, however, the improvement of general housing standards must also be considered.

It is accepted that motor handicapped children need extra housing space. They often need equipment like exer-

cise mats, training balls, adapted velocipedes, walkers and sometimes wheel chairs, etc. Special adaptation is often needed to make the dwelling practical.

A motor handicapped child has influence on the family life in several ways. In the present study it was common that parents had the child in their (parental) bedroom. It should be noted that the severeness of the motor handicap was far more important for having the child sharing the bedroom with parents than was low age or epilepsy.

Special adaptation of dwellings and more often, having them situated on the ground floor, would have meant that more children cared for in institutions could have visited their homes; an view also expressed by interviewed families.

Physical difficulties are apparent for children with a motor handicap living above ground floor. However, psychological problems also exist, e.g. when the child can only reach the apartment with the help of other people, presenting the child with difficulties in gaining independence.

CHAPTER IX

HANDICAP ORGANIZATIONS AND HEALTH SERVICES

Through special handicap organizations parents of handicapped children have opportunities to meet other parents with the same or similar problems. At conferences and courses they can learn more, have extra contact with medical, pedagogic and social authorities and work for the dissemination of knowledge to other parents, and to people in general. They can actively contribute to development of better habilitation conditions for handicapped children.

Most children with motor handicaps have need of special resources. Like all other children they have the right to benefit from the ordinary child health and the medical services.

Membership of handicap organizations

Half the families of children with CP or SBC (n=197) were members of one (41.7%) or more (9.6%) handicap organizations. Most were members of RBU (Riksförbundet för Rörelsehindrade Barn och Ungdomar, i.e. The Swedish Association for Motor Handicapped Children and Young People), the others of FUB (Riksförbundet för Utvecklingsstörda Barn, Ungdomar och Vuxna, i.e. The Swedish Association for Mentally Retarded Children, Young People and Adults) or both these associations.

Child health centres

Child health centres for preschool children were established in Sweden at the beginning of the 1940s. According to regulations, the health centres should conduct examinations to assess the children's physical, mental and social development from birth until starting school at age 7.

In the present study 64 children were preschoolers (born 1969-72). Five of them were cared for in institutions for severely mentally retarded. Of the rest, 57.6% (34/59) had visited the child health centres within the last two years. This may be compared to 81.9% of all preschoolers in Sweden (78).

Health control of four-year-old children

Pioneer work in health control of four-year-old children was done in the late 60s by Köhler in parts of the MLL area (40).

Since 1969 all four-year-old children in Sweden are offered a special, comprehensive health examination.

Some children in the present study had already passed the age of 4 years when this examination was introduced. Others at 4 years of age were permanently cared for in institutions for severely mentally retarded. Thus, 106 of the children with CP or SBC had had an opportunity to attend this health examination for 4 year-olds; 62.3% (66/106) had participated. The parents of 38 children (35.8%) felt no need for

this special examination because of their frequent contact with medical care services, due to the handicap of the child. Only parents of 2 children did not want to participate in the control. On average, 3.1% in MLL at that time were non-attenders (86).

Parents' contact with medical care services when concerned about the child's handicap or an acute illness

Fig. 11 illustrates where the parents sought medical examination and information about the child's handicap - and where they turned to for help when concerned about an acute illness in their child with CP or SBC (n=197). When worrying about the child's handicap most parents (66%) contacted the habilitation doctor. The parents of 4 of the children thought they had "no good contact" in this respect.

When the handicapped child had an acute illness most often the district medical service (42%) had been contacted. The habilitation doctor had in this situation been consulted only by 8%. More frequently the parents had turned to any paediatrician (34%). Families of 23 children felt "no need" for medical contact. Of these (23 children) 11 were cared for in institutions where they received their medical care. The other 12 children had not been so ill that their parents had consulted a doctor.

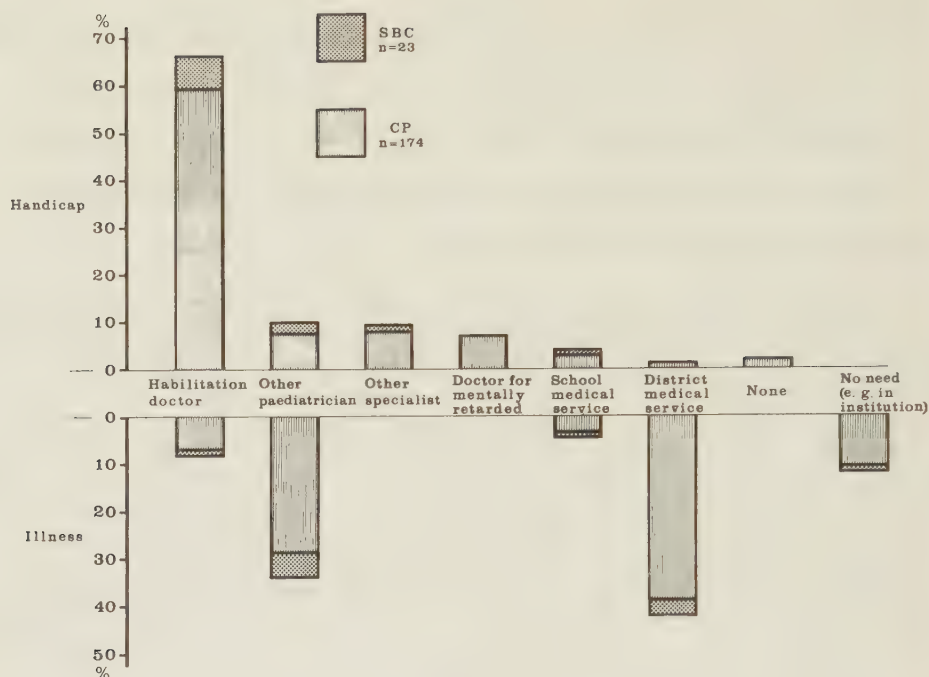


Fig. 11. Parents' contact with medical care services when concerned about the child's handicap or an acute illness.

DISCUSSION

Parents of motor handicapped children in MLL are informed early by the habilitation team of the existence of handicap organizations. However, only half of the parents were members of these organizations in 1976 as well as 1966 (25). Certainly, there are many parents of handicapped children who do not wish or do not have the strength, to be engaged in these organizations. Others are active members, sometimes driven by a strong wish to help to achieve better

conditions for other handicapped children as well as their own. There may be a channeling of aggressive energy in their striving - through local, or central co-ordinating, organizations - to influence the central, regional and local authorities. Through work of this kind parents of handicapped children have over the years formed powerful pressure groups (and still can do so), that contribute to the development of better habilitation facilities.

The attendance at the organized preventive health service, the Child Health Centres, was relatively high. In Sweden practically all children aged one year or under attended Child Health Centres. Children of this age group (as well as children 2-3 years of age) are included in the official statistics (78) but not in the present study. Therefore, the real difference in rate of attendance of the children in the present study and the average - for corresponding age groups - is less than the observed 24.3% (81.9% minus 57.6%). Thus, the attendance at the organized preventive health services, the Child Health Centres, was quite high. The support and help that this service can offer in various fields such as ophtalmic and auditory screening, dental health, upbringing, are even more important for a handicapped child and its family. Therefore, if the parents do not want to visit an ordinary Child Health Centre, these services should be provided in other ways, co-ordinated by the habilitation team. No child, especially if handicapped - with less developed

compensatory ability - should be deprived of these services.

McAndrew reported that parents felt keenly that only doctors who had frequent contact with their child, or had specialist knowledge of CP or SBC, could adequately understand their child's condition (77).

It seems quite natural that parents of most of the children with CP or SBC consulted the habilitation doctor or other specialists when wishing basic knowledge about their child's handicap or when concerned about problems related to it. The habilitation doctor is often consulted when there are multifactorial problems worrying the parents. He/she has also to act as an adviser and arrange referrals (e.g. to the neurosurgical department when shunt troubles are suspected, to the child orthopedic surgeon when there are troubles within the orthopedic sphere, etc.). He/she has also to conduct activities like physio- and occupational therapy. The handicapped child and its parents are guided and supported by the habilitation team concerning the contact with preschool and school as well as other authorities in society.

When concerned about an acute illness in the child, parents sometimes turned to the habilitation doctor, more often to any paediatrician or consulted the district medical service. In this way, it was always possible to find a doctor on duty, often near home, a doctor with enough knowledge of infectious and other acute diseases, in whom the parents could place their trust.

CHAPTER X

INCOME AND FINANCIAL SUPPORT

In addition to the practical and psychological problems for a family with a handicapped child, there is always an increased economic burden, the extent of which depends on the prerequisites of the individual family. In some societies nearly half the families with a chronically sick child have significant financial difficulties as a consequence of the child's condition (71). Therefore, affluent societies try to compensate these families economically in some way.

In most counties in Sweden social and medical services are given without extra costs to the family. Thus, in MLL treatment such as physio- and speech therapy is included in this free service. Also, the expenses for transportation in connection with these activities, as well as all aids needed because of the handicap, are free of charge.

Furthermore, a number of allowances are available.

Income

Married parents of children with CP or SBC had a lower total income than the average in MLL (80) (Table 46), especially when only one of the parents was the wage-earner. The income for unmarried parents with a child with CP or SBC was not lower than the average.

Table 46. Mean income (SKr^a) 1976 for parents of children with CP or SBC compared to the average in MLL

	<u>MARRIED PARENTS living together</u>		UNMARRIED
	both wage- earners	one wage- earner	PARENT
Parents of children with CP or SBC	76 691	44 842	33 579
The average parents in MLL (80)	87 600	60 900	31 200

General family allowance

Every Swedish mother (or her "deputy") gets General Family Allowance automatically for children under 16 years of age (1976 = 1 800 SKr^a) per annum). The allowance is not liable to income tax.

General rent allowances for families with children

Families can apply for State and also Municipal Rent Allowances. These allowances are related to the amount of (high) rent and (low) taxable income. It is dependent also on the number of children.

Handicap child care allowance

In Sweden handicap child care allowance from the National Health Insurance is payable to the parent mainly re-

^a) 100 Swedish crowns (SKr) = ¥ 22.7; ¥ 11.87 (1976, April 1)

sponsible for the care of the child under 16, who, by reason of handicap or sickness is in need of special care and attention for more than 6 months. It is not subject to any economical means test. The full allowance in 1976 was 13 318 SKr per annum. It is paid out in full or half depending on the extent of care and attention needed by the child and the amount of extra expense incurred. The sum is taxable and qualifies the child-minder for supplementary pension (ATP).

In addition to this governmental support, most county councils in Sweden have supplementary allowance for handicapped children. This allowance is neither subject to economical means test, nor is it liable to income tax. The amount is based on the burden of care of the handicapped child. In MLL (1976) the sum varied between 200 and 500 SKr per month.

More than half (117/197 =59.4%) of the families who had children with CP or SBC received economical support by either one (25.9%) or both (33.5%) of the two forms of handicapped child care allowances (Table 47).

Fifteen of the 80 families were disqualified for receiving allowance. Ten of them had children cared for in institutions all year round; 4 children were in foster homes - and thus not eligible. One young man having reached the age of 16, had a disability pension.

One family was unaware of the possibility of getting

Table 47. Handicap child care allowances among children with CP or SBC in MLL

HANDICAP CHILD CARE ALLOWANCE						
	National insurance		National insurance and county council	County council only	Any allowance	
	Half	Full				
	n	n	n	n	n	(%)
CP n=174	2	41	50	3	96	(55.2)
SBC n=23	1	3	16	1	21	(91.3)
Total n=197	3	44	66	4	117	(59.4)

child care allowance; 3 had not then applied while 2 others were awaiting decisions. Three families were refused an allowance because the handicap of the child was slight. The parents of the remaining children with CP or SBC ($56/197 = 28.4\%$) regarded themselves as not being entitled to an allowance because the child had only a slight-moderate handicap. In 4 of these families - as well as those 3 who were going to apply - the social worker found the families to be well-qualified for an allowance.

The opinion of the parents and the social worker on the amount of handicap allowance sometimes diverged. The social worker considered the allowance to be unreasonably

high for 8 families; in 3 cases the parents agreed. In 17 families (11 without + 6 with this allowance) the social worker found the allowance to be too small; in 6 cases the parents disagreed!

Allowance for housing adjustment

Housing adjustments were made with the help of an allowance in 10.7% of the families with children with CP or SBC. In another 9.6% this had been done without an allowance (Chapter VIII).

Municipality handicap rent allowance

Some municipalities have a special municipal handicap rent allowance. This is subject to income means test. The purpose of this allowance is to make it easier for the families with handicapped members to obtain a better housing standard and consequently compensation for higher living costs.

About half of the families with children with CP or SBC were not entitled to this allowance because the handicap was "too small" to have any influence on housing costs. About one fourth did not have this allowance in their municipality.

Six of the families who had children with CP or SBC had this municipal handicap rent allowance (Table 48). Two were awaiting a decision while 2 were denied it. Those (14%) who had not applied either regarded their income

Table 48. Municipality handicap rent allowance for families with children with CP or SBC in MLL

	n
Applied	
- getting allowance	6
- awaiting decision	2
- denied	2
Not available in the municipality	44
Not entitled, because of the degree of handicap	93
Not applied	26
Did not know of this allowance	14
Total	187

as too high or did not regard themselves as having higher housing costs than they normally would have had. Fourteen families were not aware of this special allowance until the interview, however, most of them would not have qualified for the allowance anyway.

DISCUSSION

The distribution of the parents of children with CP or SBC according to education and social group was the same as the average parents in MLL. For married parents of children with CP or SBC, the total income was lower than

the average. The main reason for this was the lower frequency of mothers working outside the home, especially full-time. However, the total, taxable, yearly income for parents of 70 (35.5%), of the children with CP or SBC, was increased by the tax-free county council handicap child care allowance. The care of the motor handicapped child did not in any case lead to severe economical hardship. Payment of the general allowance was always - and special ones mostly - satisfactory. The system of different allowances is well established in Sweden, but sometimes parents do not know about it. Therefore, the social worker has an important duty to inform them.

For some motor handicapped children the need for economic help will increase as they grow older. Others may - by age and training - become more independent than they were at the time of the first application for handicap child care allowance. Thus, it is important that the social worker of the habilitation team also follows up and re-evaluates the need for allowance and helps families with motor handicapped children to get the proper allowances to which they are entitled.

The often felt shortage of time for the habilitation social worker was confirmed at the investigation interviews. Thus, it was apparent that several families needed more information, therapeutical talks and guidance in applying for different allowances.

CHAPTER XI

GENERAL SUMMARY AND CONCLUSIONS

Parallel with improved socio-economic conditions, including better nutrition and housing, infant mortality and morbidity have dramatically diminished in industrialized countries. There are no serious epidemics, growth and development are satisfactory and the health care of children is well developed.

The panorama of childhood disease has changed so that chronic diseases or handicaps have become a relatively more important and noticeable health hazard.

Number and frequencies, severity of motor handicaps

Related to population the number of motor handicapped children was much the same in the present study compared to the analogous one made 10 years previously.

The prevalence of SBC had increased, because of active, surgical treatment, while the incidence and prevalence of CP were unchanged. However, more of the children had a severe motor handicap, most often due to an early, severe brain damage.

Associated handicaps, severity of total handicaps

Almost 80% of the children had associated handicaps; half of them had two or more associated handicaps. Speech problems, mental retardation and epilepsy were most

frequent gross deviations; but minor neurological disturbance of concentration, perception, etc. were also common.

Associated handicaps as well as severe total handicaps (43%) were more frequent in the present study compared to 10 years earlier. There are different explanations to consider when trying to find the reasons for this increase. One is the efficiency of the neonatal intensive care that has lowered the neonatal mortality, at least for a time, more in MLL than nationally, and may thus have implied early and very active resuscitation of a number of severely brain damaged newborns. This may agree with Davies' theory that intensive neonatal care in the beginning leads to increased rates of handicaps - which later will decrease again. Recently Lindroth et al. have shown that progress in obstetric and intensive neonatal care in Lund has lowered the incidence of neuro development sequelae in certain risk groups.

In spite of more severely totally handicapped children in the present study compared to the 1966 survey, there were not more children depending on help from other people in respect of ADL in the 1976 study, reflecting an improved ADL training programme.

Care at home - society support

The emotional and social development of children, also handicapped children, are better satisfied in the family

homes than in institutions. Therefore, families are encouraged to take care of the handicapped children; they are receiving free physiotherapy and other specialized medical care, they are given priority to nurseries and Kindergartens, and also personal assistance in preschools and schools when needed.

The family is also supported by various allowances.

Already in 1966 most of the motor handicapped children were cared for in their family homes, in 1976 even more, 89.5%, had this privilege.

The family

Having a child with a motor handicap has an impact on the whole family, often with heavy demands, especially on the mothers. The working capacity of the fathers was not reduced; more of the mothers, however, were not working outside the home and especially not working full-time compared to the average.

The mothers attended organized leisure time activities to the same extent as the fathers. More of the mothers, compared to the average mother, did not work, study, or participate in organized leisure time activities, when the child was young.

Resources were very limited for occasional relief of families with motor handicapped children. Residential care was hardly available at all - unless the child

was severely mentally retarded. There was a great need for occasional relief also for mothers of the other motor handicapped children. The parents expressed a strong wish for the services of specially educated "baby-sitters" with experience of handicapped children, a desirable service in helping to reduce some of the family strain - but one which is not yet available.

Marital status - divorce rate

Children with CP or SBC lived in nuclear families to the same extent as other children in the area (89%). Most parents were married. There was no increased divorce rate. The reasons for this are certainly multiple and not easily found. However, it is likely that weak or bad relations between parents cannot withstand the great strain that a handicapped child places on the family; on the other hand, marital relations may be strengthened and preserved by the parents' joint efforts to give optimal care to the handicapped child.

Living standard

The vast majority lived on ground level.

The standard of dwelling with regard to living in small houses, number of rooms and all modern conveniences, was high; higher than for the average child family and higher than that of the 1966 survey.

Preschool

In 1975 a preschool act was passed, offering all children a place in the municipal part-time preschools during the year preceeding school start. It also gave priority to children who need extra training and stimulation, e.g. children with handicaps. Due to this law and also to better preschool resources generally, as much as 90% of the children with CP or SBC of preschool age participated in organized preschool activities - about double the rate found in the 1966 study. Thus, there has been a most satisfactory development of preschooling - not least for the needs of children with motor handicaps.

School

All children of school age - also the most handicapped - were included in the educational system, with individual adaptations to their ability when needed. Two thirds of the children with CP or SBC with normal intellectual capacity attended ordinary classes. The remaining children, who were not individually integrated, were educated in special classes, usually situated in ordinary schools. The need for personal assistance in school, as well as the need for transportation to and from school, was generally satisfactorily supplied.

Thus, there has been a most positive development also of the school conditions for motor handicapped children - very few now needing education in residential schools.

Integration

Primary integration in ordinary preschools and schools, supplemented with personal assistance and special care and treatment by mobile habilitation teams visiting them, is recommended.

Leisure time activities

The majority (76%) of the children with CP or SBC living at home participated once a week or more often in family activities outside the home. More than half of the school children attended organized leisure time activities once a week or more.

About 40% had daily contact with their peers outside preschool or school.

Although these figures point to a satisfactory participation in social activities for most of the handicapped children, it is obvious that some of them did not enjoy a satisfactory social life. Extensive encouragement and facilitation of handicapped children's peer contact in and outside school is important.

Shortage of habilitation resources

There was a general shortage of habilitation staff, especially for work in family homes, preschools and schools. The parents themselves had to perform a great deal of the training at home; about one third complained that they felt strained by the demands (87).

Habilitation of motor handicapped children in MLL -
the future

In times of severe economic constraints there is little hope of increasing staff and facilities for habilitation.

Through preventive medicine, genetic counselling, intense supervision of deliveries and intensive neonatal care, the prevalence of handicapped children is likely - at least to some extent - to diminish. However, the high and increased frequency of associated, often multiple and severe, handicaps in this study, demands consideration. Benefits and hazards of new methods of treatment and care must be studied further and evaluated. There is an apparent need for more psychological studies of motor handicapped children.

Further improvement of the care of motor handicapped children, more habilitation staff and other facilities are needed, and can be attained mainly by rationalization and reallocation of existing services. There is a need for, and reasonable prospects of achieving, better coordination of habilitation services for children with different handicaps during the 1980s.

SUMMARY

Children with motor handicaps seem to have existed throughout history. Epoch-making investigations of children with cerebral palsy were done in the 19th century. Due to the decreased child mortality and morbidity the relative importance of motor handicapped children's problems, the interest for and also the facilities for the care of these children have obviously increased in this century, especially during the last decades.

PART ONE

SUMMARY CHAPTER I

NUMBER, FREQUENCIES, SEX, SEVERITY OF MOTOR AND MENTAL HANDICAPS

In a Swedish county (MLL; population 0.5 million) in 1976 all the 266 motor handicapped children (aged 4-16) were investigated. Most of them, 68.8%, had cerebral palsy (CP), 9% spina bifida cystica (SBC) and 22.2% other motor handicaps (OMH). The incidence of CP was 1.9 per 1 000, and of SBC, 0.6 per 1 000. There was an excess of boys. One third of the children were severely motor handicapped; one fourth were mentally retarded, - one fifth severely mentally retarded. Compared with an analogous study by the same investigator, in the same area, 10 years earlier, the same proportion of children in the area had a motor handicap.

Mental retardation was equally common among them, but more children were severely motor and severely mentally handicapped in the present study.

SUMMARY CHAPTER II

ASSOCIATED HANDICAPS, ACTIVITIES IN DAILY LIVING (ADL) AND TOTAL HANDICAPS IN MOTOR HANDICAPPED CHILDREN

Associated handicaps are frequent in motor handicapped children. Four out of five of the children with CP or SBC had associated handicaps; more than half of them had two or more associated handicaps. Among children with CP, the most frequent associated handicap was speech problems, followed by mental retardation, concentration problems and epilepsy. Epilepsy was directly correlated to mental retardation and to severity of the motor handicap.

While the motor handicap was severe for one third of the children, two out of five with CP or OMH and two out of three with SBC, had a severe total handicap.

Similarities were found between the present study and the analogous one made 10 years earlier. Thus, vision, hearing and speech disturbances, as well as mental retardation, were equally common. Some - especially psychological problems - were noted in a higher rate in the present study. In spite of more children being severely totally handicapped in the last series, the figures

regarding ADL-dependency were similar. This is likely to reflect a better ADL training nowadays than earlier.

SUMMARY CHAPTER III

FAMILY AND DELIVERY CONDITIONS

Families with motor handicapped children were socio-economically distributed in the same way as child families generally are in Sweden. There was an excess of mental retardation and severe motor handicaps among children originating from the lowest socio-economic group.

There was no excess of older mothers, nor was there any reduction of the number of children in the families. The frequency of severe motor and severe total handicaps was not increased when the child was the only one in the family, nor if he/she was the first or the last of siblings. More children with CP than others in the study were first-born.

There was a highly significant excess of twins among the children with CP.

All the children with CP and 97.5% of the others were delivered in hospitals, 70% at maternity hospitals. The rate of caesarean section, vacuum extraction and forceps deliveries was for the CP group twice or more that of the average.

Figures for breech deliveries were high, especially

among children with SBC.

There was a preponderance of low birth weight among the children with CP - especially of weight 2 000 g or less among the spastic diplegic children. Most of them were appropriate for gestational age (AGA), i.e. born after a short gestation. The dyskinetic CP children had the highest rate (20.6%) of lightness for gestational age.

Perinatal brain damage was the most common cause of CP (48.1%), unchanged when compared to the investigation 10 years earlier in the same area. There was a decrease of postnatal and of untraceable causes and an increase of prenatal causes of CP. Remarkable similarities were found in distribution of pre-, peri-, postnatal and untraceable causes of CP in this series compared to other recent reports.

PART TWO

SUMMARY CHAPTER IV

PARENTS OF CHILDREN WITH CP OR SBC

The vast majority of children (89.3%) were living in nuclear families; most parents were married (84.2%) or living together in an intimate, long established relationship - cohabitation (5.1%).

The divorce rate did not differ from the average.

Social class, nationality, age and level of education

of parents was the same as for the average parents.

The working capacity of fathers was not reduced, while more of the mothers were not working outside the home and especially not working full-time, compared to the average woman in MLL.

Most parents, mothers to the same extent as fathers, did attend organized leisure time activities. When mothers were without work, studies and organized leisure time activities, the child was often young - at the preschool age.

Relatives - especially maternal grand-mothers - were often engaged as foster parents, for regular day-care and as "baby-sitters". Even children 12 years of age or older needed "baby-sitters". A service greatly desired by the parents was specially educated "baby-sitters" with experience of handicapped children.

SUMMARY CHAPTER V

CHILDREN IN PRESCHOOLS -

DAY NURSERIES AND KINDERGARTENS

The Swedish preschool system is presented.

Sixty-four of the children with CP or SBC were of pre-school age. Most of them (89.1%) were participating in different preschool activities, 40.6% in ordinary day nurseries or Kindergartens. A total of 32.8% attended

special Kindergartens for motor handicapped, one fourth of them also participated in other preschool activities. The County Council Board for Provisions and Services to the Mentally Retarded had arranged activities for all the mentally retarded motor handicapped preschoolers.

School start was delayed for 4 children, all mentally retarded and attending special preschools.

The preschool buildings were suitable, the need for assistance well met and the transportation system functioning satisfactorily.

Children with CP or SBC were more frequently engaged in preschool activities than the average child in MLL. Some went to more than one type of preschool, sometimes a distance from home. The advantages and disadvantages of going to different preschools are discussed.

Primary integration in ordinary preschools, supplemented with personal assistance and special care and treatment by mobile habilitation teams visiting them, is recommended.

SUMMARY CHAPTER VI

CHILDREN IN SCHOOL

All children in Sweden are guaranteed education. The school system is presented.

Parents of 133 schoolchildren with CP or SBC were interviewed. Four of the mentally retarded children were

cared for in special preschools; 30 had special education for mentally retarded. The 99 mentally normal were educated at comprehensive school level. Most (69.7%) were individually integrated into ordinary classes; 16.2% were educated in special classes for motor handicapped.

Most school buildings were sufficiently adapted for children with CP, less often for children with SBC. The transportation to and from school as well as the need for personal assistance was well catered for.

Individual integration into ordinary classes in well adapted schools and with extra personal and physical support is recommended for most of the children with motor handicaps. To achieve this goal more educational and habilitation resources are needed.

SUMMARY CHAPTER VII

LEISURE TIME ACTIVITIES

The vast majority (94.4%) of the children with CP or SBC participated in family activities outside home; two thirds of the children living at home did so once a week or more often.

Of the schoolchildren, more than half participated in organized leisure time activities, one third in two or more activities per week. Swimming was the most frequently attended sports activity.

Half of the older schoolchildren ($\geq$ 12 years of age), living at home, participating in free leisure time activities such as going to movies, etc. Some of the older schoolchildren, with slight total handicaps, seem to be overprotected and withdrawn from free leisure time activities.

The vast majority of children with CP or SBC (86.3%) had leisure time contact with other children of their own age at least every month; two fifths had it roughly daily.

Less than one fifth of the families with schoolchildren took advantage of the municipal transport service for leisure time activities; most parents preferring to use their own car.

SUMMARY CHAPTER VIII

HOUSING

The vast majority (89.5%) of the children with CP or SBC in MLL were living in family homes. The standard of dwelling - with regard to living in small houses, number of rooms and having all modern conveniences - was high, higher than for the average child family and higher than that of the 1966 survey.

The majority (77.7%) lived with ground level access. One fifth of the dwellings were specially adapted, half

of them with the help of a special allowance.

Nearly one fifth of the children shared bedrooms with their parents; a proportion which reached one third among the severely motor handicapped.

SUMMARY CHAPTER IX

HANDICAP ORGANIZATIONS AND HEALTH SERVICES

Half of the parents were members of handicap organizations which is the same rate as in the 1966 survey.

There was a relatively high number of children with CP or SBC who attended ordinary Child Health Centres, also for the special health examination for four-year-olds.

Most parents contacted the habilitation doctor when concerned about the child's handicap. When worrying about an acute illness they more often turned to any paediatrician or to the district medical service.

SUMMARY CHAPTER X

INCOME AND FINANCIAL SUPPORT

In addition to the other problems for a family with a handicapped child there is an increased economic burden. Therefore, in most counties in Sweden social and medical services are given without extra cost to these families. Necessary aids are free of charge. A number of allowances are available.

Married parents of children with CP or SBC had a lower total income than the average child family in MLL.

Rules for general and special allowances are presented. About 60% of the families who had children with CP or SBC had some form of handicapped child care allowance.

The important role of the habilitation social worker is elucidated.

SUMMARY CHAPTER XI

GENERAL SUMMARY AND CONCLUSIONS

This chapter comprises a general summary with discussion, conclusions and ideas of the future.

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